

VISUAL SUPPORT SYSTEMS: A
QUALITATIVE EVALUATION OF THE
SUPPORT PROVIDED TO PARENTS OF
CHILDREN WITH AUTISM

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ABSTRACT

Since the 1990s, parent-professional partnership working has seen a shift from a professionally driven model, where professionals had a power-over relationship with parents, to an empowerment model, which allows power to be created and developed through relationships. This move has enabled families of children with *Autism Spectrum Disorder* (ASD) to have their priorities attended to when planning goals and intervention around *Visual Support Systems* (VSSs). However, there is debate as to whether a collective empowerment model of service delivery is being used effectively when planning and implementing goals around VSSs. There is also lack of information on the perceived benefits of using VSSs with children with ASD.

This study aimed to explore the parental perspective and negotiation of responsibility with professionals when planning goals and service provision around VSSs and to elicit parents' views on the changes they perceived in their children and their own abilities following the support received.

Adopting a qualitative, case study methodological strategy, a total of ten participants participated in either a focus group or semi-structured interview. Thematic analysis was used to analyse data. Three major themes emerged from the data: parent-professional partnership, perceived changes in abilities and skills, and experiences of using VSSs. Sub-themes are also presented, including shared planning and decision-making, enablers and barriers of using VSSs, and professionals' qualities.

Implications for practice suggest: the need for regular discussions with parents in relation to VSSs; further examination of service delivery; the need for professionals to draw on parent-professional partnership literature; the implementation of strategies to encourage parental engagement and prevent possible barriers.

Keywords: Autism Spectrum Disorder (ASD), Visual Support Systems (VSSs), Parent-Professional Partnership.

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Glossary of key terms

Autism: a lifelong, developmental disorder. Historically, different diagnostic labels have been used, such as: Autism, Autism Spectrum Disorder (ASD), High-Functioning Autism. This is due to the different diagnostic manuals and tools used. Autism Spectrum Disorder (ASD) is the most common term used due to changes in diagnostic manuals. The terms ‘Autism’ and ‘Autism Spectrum Disorders’ are used interchangeably throughout the thesis to refer to the same disorder.

Autism Spectrum Disorder (ASD): a diagnostic term for a developmental disability impacting development in the areas of social communication skills, social interaction, repetitive/restricted behaviour/interests or non-compliant behaviour.

Diagnostic and Statistical Manual of Mental Disorders (DSM): a diagnostic manual offering criteria for the diagnosis of mental disorders. Clinicians and researchers often use this.

Picture Exchange Communication System (PECS): An augmentative communication system. Children are taught to communicate a need by exchanging a picture for a desired item.

Social Communication Disorder (SCD): a diagnostic term for a disorder related to difficulties in the areas of social interaction, social understanding and pragmatics.

Visual Support System/s (VSS/s): a visual teaching method traditionally used with children with autism. Various terms are used throughout literature to describe these therapy tools. For example: visuals, visual aids, and visual supports. The term *visual support system/s* is used throughout this thesis.

Visual Schedule: a type of visual support system used with children with autism to reduce anxiety and aid comprehension of a routine.

Parent-Professional Partnership/Collaboration: a term used to describe the relationship between parents and professionals. The main processes involved include: equal opportunity, equal knowledge, sharing information, shared purpose, mutual respect, and negotiation. The terms ‘Parent-Professional Collaboration’ and ‘Parent-Professional Partnership’ are used interchangeably throughout the thesis.

Professional: a person qualified in a health or education profession.

Collective Empowerment Model: a model of service delivery that includes families and professionals increasing their knowledge and skills to attain mutually agreed upon goals.

Multi-Agency: involves several agencies/organisations working with a

child/family but not necessarily together. However, current legislation and guidance in the Republic of Ireland tends to use this term to mean working together in a coordinated way. Throughout the thesis, the terms as they appear in the references provided have been used.

Multi-Disciplinary: involves more than one discipline working with a child/family but not necessarily together. However, current legislation and guidance in the Republic of Ireland tends to use this term to mean working together in a coordinated way. Throughout the thesis, the terms as they appear in the references provided have been used.

Trans-disciplinary: involves more than one professional working with a family, sharing information, learning together, and seeking to work beyond traditional professional boundaries. It is believed that the service under exploration worked as a trans-disciplinary team.

Boardmaker®: is a software used to generate and print pictures for visual support systems. During the interviews, some participants use the term 'Boardmaker®' to refer to this software. The visual images presented throughout the thesis appear to contain images using this software. The Picture Communication Symbols©1981-2015 by Mayer-Johnson LLC - a Tobii Dynavox company. All Rights Reserved Worldwide. Boardmaker® is a trademark of Mayer-Johnson LLC. The images used throughout this thesis are for non-profit, educational and research purposes only. They were selected to inform the readers of what visual support systems may look like. References of the websites used to obtain the images are provided in the reference list.

1.0. INTRODUCTION

1.1. Overview

This foreword provides a general introduction to the key aspects involved in this research study. It discusses the research topic, the motivation behind the research, and includes the study's aims and research questions. A summary of the contents and structure of this thesis is also presented.

1.2. General motivation of the study

1.2.1. Defining terms: Autism Spectrum Disorder and Visual Support Systems

Children with *Autism Spectrum Disorder* (ASD) typically demonstrate difficulties with verbal and nonverbal communication, social communication, and behaviour (Anagnostou and Brian 2015; American Psychiatric Association 2013). Based on the definition by the *National Autistic Society* (NAS) (2016), ASD is a developmental disability impacting development in the areas of social communication skills and social interaction. The most recent *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-V) (American Psychiatric Association 2013), typically used to diagnose the disorder, includes a series of specifiers to describe the characteristics demonstrated by each individual child. A severity matrix is also presented in the manual. Additionally, children with ASD may present with or without cognitive impairment and/or with or without language impairment. More detailed criteria are presented in Appendix 1. In summary, children with ASD will typically present with difficulties in social interaction and communication often with repetitive and stereotyped behaviour, and sensory abnormalities.

Due to these difficulties, a variety of intervention techniques and approaches are available to alleviate obstacles children with ASD may encounter. The treatment methods can often be multi-dimensional and complex, but are commonly required throughout the life span of a person with ASD (Goldstein

and DeVries 2013). Although there is no one, top therapy programme or best method for assisting children, due to the uniqueness of individuals with ASD (NAS 2017), visual teaching methods are often recommended (Hodgdon 2000; Rao and Gagie 2006). Various terms have been used to describe these visual teaching methods. For the purpose of this thesis, the term *Visual Support Systems* (VSSs) will be used throughout to cover terms such as: Visuals, Visual Aids, and Visual Supports.

VSSs are evidence-based therapy tools (Johnston et al. 2003; Morrison et al. 2002) typically used with children with ASD, to alleviate behaviour and improve communication skills (Gray 1993). VSSs can be any tool presented visually and generally tend to include, but are not limited to, the use of a drawing/photograph depicting an object or the steps involved in a task. They can be created, by both parents and professionals, in numerous, different ways based on the strengths and needs of the child. Additionally, they can be used across settings to support children with ASD (National Research Council 2001). An example is presented in Figure 1. Other examples and further information on the effectiveness of this approach can be found in Chapter 2.

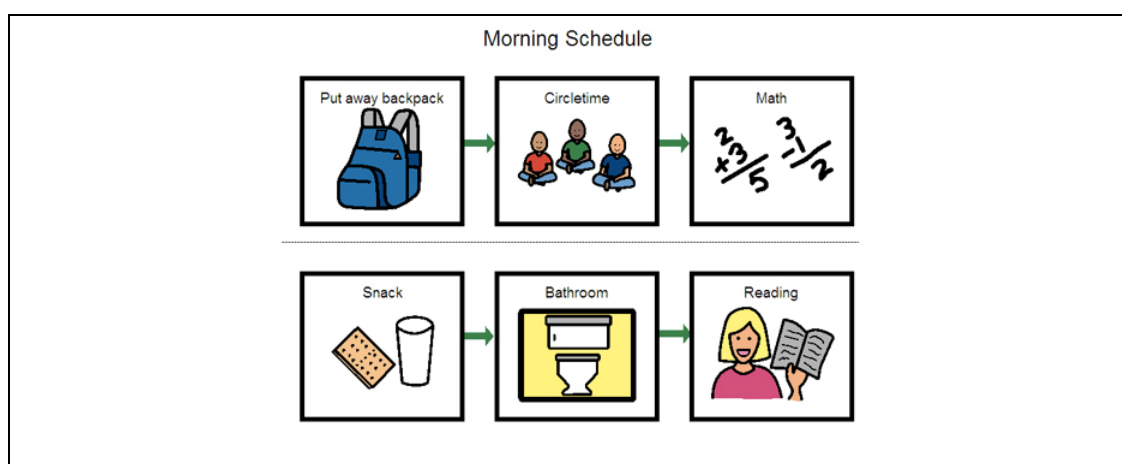


Figure 1. Visual schedule depicting morning events at school (Applied Behavioural Strategies 2016). *Often used to help a child with ASD understand what will happen first and next, thus reducing anxiety and aiding comprehension of a routine.*

One of the benefits of using VSSs in children's natural environments, is that parents save themselves time and stress as difficult behaviours become more manageable (Davies 2008). Additionally, VSSs decrease dependence and overreliance on adults by promoting children's independence skills (Banda et al. 2009). Despite the somewhat time-consuming process of setting up VSSs, parents also enhance their children's communication skills when they use these systems with their children (NAS 2003). VSSs are therefore developed to meet individual needs, abilities, ages, and interests of the children (Cohen and Sloan 2007). Indeed the use of VSSs with young children with ASD, has been the focus of numerous research studies proving effective in improving task engagement, enhancing social interaction and developing play skills (Krantz and McClannahan 1998; Massey and Wheeler 2000; Morrison et al. 2002).

1.2.2. Overview of the need for research

Professionals working in the field of autism, in various settings, frequently provide parents with support around designing and implementing these visual therapy tools. In an autism health service within the Republic of Ireland, a parent-professional partnership model is frequently employed to determine the strengths and needs of the child, agree on goals, and establish care pathways. More specifically, autism services endeavor to employ a *collective empowerment model of service delivery* when planning and determining goals around VSSs. Turnbull et al. (2000, p. 641), reflecting on the work of various scholars, state that: "the contemporary focus is collective empowerment, in which all participants (i.e. professionals and families) increase their capacity and mastery over the resources needed to achieve mutually desired outcomes". Parents and professionals are assisted by existing statutory and recommended support networks to help each other and become collectively empowered so as to work towards agreed goals for the child (Meggitt 1997).

The ideal parent-professional model of service delivery in early intervention, for children with disabilities, has been the focus of numerous research articles and books since the 1990s (e.g. Case 2000; Dunst 2010; Dunst and Trivette 1996; Turnbull et al. 2000). The concept of parent-professional partnership as it applies to working with families of children with disabilities has been examined considerably from both research and theoretical perspectives. Different models and definitions exist; hence no consensual definition of partnership working has been established (2009). Models such as the *parent training model* and the *psychotherapy model*, as well as definitions of partnership, are discussed in the literature review, Chapter 2. Although currently importance is placed on a collective empowerment model of service delivery, other models of partnership, such as the psychotherapy model discussed later, are still apparent in everyday practice (Papatheodorou 2005). The collective empowerment model is indeed comparatively new in the progression of parent-professional partnership models of service delivery. Published accounts from parents who have participated in early intervention programmes for children with ASD with the aim of collective empowerment are limited.

From an education perspective in the United Kingdom for example, whilst it is widely accepted that working with parents is of great value, the concept is still being reinforced in policies such as: the *Statutory Framework for the Early Years Foundation Stage* (Department for Education 2014), *The Children and Families Act* (Department of Health 2014), and the *Special Educational Needs and Disability Code of Practice 0-25 years* (Department for Education and Department of Health 2015). With the advent of parent-centred practice and legislative changes in the Republic of Ireland mandating the importance of parent involvement when dealing with young children's special educational needs (Department of Education and Science 1998; Government of Ireland 2004), professionals have been encouraged to work closely with parents and families (National Council for Special Education 2006; National Council for Special Education 2010). In Ireland, legislation

relating to children with special educational needs is not extensive, although there have been several government discussions, policy statements and legislation that refer to the importance of professionals working in partnership with families. For example, current Irish policy states that partnership as a concept is recommended at national level (National Parents Council Primary 2004). The historical context of the development of the Irish health service in relation to autism early intervention services is further discussed in Chapter 2. As suggested above, the term parent-professional partnership covers a very broad canvas and whilst it is suggested as an effective approach to working with parents, it may include several models of service delivery (White 2002).

As this study concerns data collected in the Republic of Ireland, Irish policies and guidance from primarily a health, but also an educational, perspective will be considered throughout. It should be noted that throughout this thesis reference is also made to policies from the United Kingdom. At the time of study, legislation relating to partnership working within the area of autism in the Republic of Ireland was limited. However, experience revealed that partnership working was evident to some extent. Whilst government legislation in the Republic of Ireland was not extensive, several discussions and team meetings reinforced the value of working in partnership with other professionals and outside agencies. For this reason, it was decided that reference would be made to policies and legislation from the United Kingdom that were being followed but not necessarily put in place. This study concerns a service that worked for the Health Service Executive within the Republic of Ireland. As described in Chapter 2, the service under exploration was indirectly involved in the delivery of services within a child's school environment. It was essential that professionals from different organisations worked together in some way. Therefore, policy and legislation concerning both health and education services is considered. Indeed, in 2010 it was recommended that agencies from both health and education worked together

(HSE 2010) and therefore it was essential that policies relating to both areas were considered.

Whilst parent-professional partnership working is expected (Education for Persons with Special Educational Needs Act 2004), it is not safe to assume that all families are similar, and what one family may see as important to partnership working, may not be the same for another. Parents are anything but equal in terms of their opinions and values, and these differences mean that they will possibly experience assistance from professionals in dissimilar ways, and have different thoughts about how they would like to work with professionals (Cunningham and Davis 1985; Wall 2003). In the context of professionals working towards a more collaborative approach with parents, where emphasis is placed on encouraging shared power for all those involved in the relationship (Wildbridge et al. 2004), it has been identified that parents' views need to be considered. Parents play a vital role in contributing to their child's overall well-being (Department of Health and Children 2000), and although professionals may strive to work in partnership with parents, partnership is often far from achieved, with some parents remaining "ignored" or seemingly "unapproachable". Additionally, because parents' wishes and resources change over time, their choice of relationship with early intervention professionals may also change (Magyar 2011).

If parents are indeed given the freedom to choose how they would like to work with professionals, one can safely say that the partnership between parents and professionals is based on the collective empowerment model of service delivery (Allen and Petr 1996). Unfortunately, it is the author's experience that often the professional decides what partnership model should be employed. Professionals' perceptions of their chosen model may be satisfactory and they may also feel that parents are content with the decision. Even if parents truly report a positive experience, McWilliam et al. (1995) argue that this may be because parents are not aware of other parent-professional models of working. For this reason, service providers

need to give consideration to the relationships they build with parents and make certain that parents have the option to truly choose how they would like to work with professionals. There is a lack of clarity around how parents feel about the support offered to them by clinicians, and for this reason parents' views need to be collected. As a researcher and clinician, the author has had numerous discussions with relevant professionals and parents questioning whether the model for setting goals and providing personally tailored support around visual systems is meeting the needs of children and their families. Whilst it is evident that parent's views around partnership working need to be considered, more specifically their views around the implementation of VSSs also need to be examined.

With the collective empowerment model as a recommendation for service delivery and the added pressure to use evidence-based therapy techniques, professionals and parents are often faced with several dilemmas (Hodge and Cole 2008). For example, partners may have different expectations in terms of goals and service provision (Lake and Billingsley 2000). Additionally, using a therapy technique that has advantages and disadvantages can put the parent-professional relationship in jeopardy. Issues with the collective empowerment model of service delivery, when determining goals and service provision around VSSs, are further discussed in Chapter 2. There has been very little in the way of eliciting parental views on the effectiveness of professionals supporting parents to understand and implement VSSs. Additionally, research tends to focus on measuring the effectiveness of support via standardized and validated instruments (Ben Chaabane et al. 2009; Kashinath et al. 2006; Krantz et al. 1993). There is uncertainty over whether or not parents feel that their skills changed following support. Additionally, it is unclear whether parents feel their child's skills improved following support. Findings from this research will help inform professionals' practice so that the needs of families can be met more effectively. If families' needs are met more effectively, this should have a significant, positive impact on the child's wellbeing (Desforges and Abouchaar 2003). The intended

audiences for this research are parents of children with ASD and professionals working in the field. Unless stated otherwise, the term “professional(s)” has been used throughout this thesis to include: teachers, therapists, health clinicians, assistants, and other relevant individuals working in the area of ASD.

1.3. Author’s experience

The researcher, a qualified Senior Speech and Language Therapist, has gained over ten years experience working in the area of ASD. The obtainment of a Masters Degree focusing on parent-professional partnership, and the experience gained throughout the years, alerted the researcher to the challenges that parents face in relation to VSSs. The parent-professional relationship has remained an area of interest for the researcher, especially when different models of practice and therapy techniques are evaluated on a daily basis. The chosen area of research was also influenced by involvement gained in a parent training committee. Experience revealed that most clinicians working in the area of autism are unsure how parents feel about the support received around VSSs. Clinicians are unsure if parents feel changes in their children’s skills and their own skills have been made following support. Views of parents therefore need to be collected to help establish what is working well and what modifications are required for future practice. An example of staff views is presented:

During a face-to-face conversation with a fellow Speech and Language Therapist, on March 1st 2013, the following was reported: *Well, I have the training and experience to teach parents how to use visual support systems. I think I know how to work with them and what works well and what doesn’t. But when I am working with parents, I don’t always know how they are feeling about the support. I see progress sometimes, but I am not sure if families see this too.*

Parental views have also been collected during therapy sessions with parents:

During a face-to-face conversation with two parents attending an autism service for their child's therapy, on April 3rd 2013, the following was reported:

It's really hard to find the time to make visual support systems. I know that my child's Speech Therapist is really trying to support my child, and me, but I'm a single mother with two children. I'm exhausted and finding the time to use a picture exchange system with my child, is sometimes just one more thing. I tried to use it, but my child still doesn't speak.

At first I thought, well this Psychologist has her own agenda, and I don't see how this is going to help my child. But then she really listened to what was important to my family and me. Together we were able to come up with a plan that worked for both of us. I really felt we had a good relationship and I'm glad I didn't give up because now I can see how my child has benefited from this.

Experience has also revealed that employing a parent-professional model for planning goals and service provision around VSSs raises questions around whether this model is meeting the needs of families. By placing the process of critical reflection on the existing model of service delivery, new knowledge will be formulated that will inform decisions about future service provision. Issues identified via experience are summarised below:

1. Clinicians are uncertain if families value what they are doing, and whether parents feel the support is a burden or beneficial.
2. Family perceptions about the effects of support on their children seem mixed. Clinicians are uncertain if families feel changes have been made in their child's skills following support.
3. Clinicians are uncertain if families feel they have understood these therapy tools and have used them following support.
4. Clinicians are uncertain whether working with families to establish goals and develop intervention plans around VSSs is actually the right thing to do.

Whilst researchers such as Turnbull and Turnbull (2002) recognise the value of professionals and parents working together, partnership working may not always be evident in practice (Keen 2007). Chapter 2 provides a more

detailed understanding of the issues associated with this parent-professional model of service delivery. The service under exploration is also described in more detail in Chapter 2.

The service under exploration, administered by an area health board, aimed to provide a multi-agency and multi-disciplinary approach to young children and adolescents with autism, their families, and school (Government of Ireland 1990). Professionals, such as Speech and Language Therapists, Psychiatrists, and Occupational Therapists, worked together to provide services to the family. Services included: training, direct clinical input, consultation, support groups and respite services. The service, set up in 1998 following a push from parents for the implementation of autism services, came at a time when the Irish economy was growing rapidly. This period, known as the 'Celtic Tiger', characterised the 1990s and early 21st century. Health services within the service under exploration were well funded; with parents having more control over the way autism services were being delivered to their children. However, the boom was subsequently dampened in a severe economic downturn in 2008. This resulted in significant budget cuts within the Health Service Executive impacting on the way services to children with autism and their families were being provided. At the time of study, there was no national policy for common autism services in Ireland. The parent-professional partnership model is therefore considered during a period of recession, cut backs, and lack of policies, resulting in possible empowerment issues between parents and professionals. The arrangement of services was being revised in 2015, following collection of data.

1.4. Research aim and questions

The aim of this particular study is therefore to examine the parental perspective and negotiation of responsibility with clinicians, as a way of meeting the needs of clients effectively. Through a review of VSSs literature and through experience working with young children with ASD and their

families, relevant questions helped guide the direction of this research. Therefore to examine what happened and understand why it happened. The study sought:

1. To establish if parents participating in the study (who decided together with professionals that support around VSSs would be provided) experienced the support to be of value/benefit and to highlight any problems with the support to aid the development of future service provision.
2. To examine the effectiveness of the support provided by exploring and eliciting the views of parents of pre-school children with autism, about changes they perceived in their child's behaviour and communication skills as a result of the support.
3. To examine the effectiveness of the support by exploring and eliciting the views of parents of pre-school children with autism, about changes they perceived in their own understanding of what VSSs are and how they are used. Also, to determine whether parents noticed changes in their own abilities to use VSSs following support.
4. To examine the model of collective empowerment, when planning goals and service provision around VSSs, through critical reflection.

1.5. Overview of the study's methodology

In order to address the purpose of the research and obtain a comprehensive picture of a particular service, the study drew upon an autism-specific early intervention service within a city health board area of the Republic of Ireland. A qualitative approach guided by the principles of case study research explored parents' views of their relationship with various professionals. There were two parts to the study: a focus group and individual semi-structured interviews. Data was collected during March and May 2014. Participants were carers whose child: 1) had a diagnosis of ASD, 2) had identified together with a trans-disciplinary team that they would like to work on a visual support therapy tool for their child, had received support around VSSs based

on their priorities, had attended the early intervention service for at least 6 months and no more than 12 months. In total, 4 participants participated in the focus group, while semi-structured interviews were conducted with 6 participants. Further details on participant selection can be found in Chapter 3.

1.6. Outline of the thesis

The thesis comprises six chapters. A brief description of each one is presented below:

Chapter one: Introduction, presented above, contained the introduction to, general motivation and rationale for the study. The aim of the study and the research questions were presented.

Chapter two: Literature Review explores the literature around the models, characteristics, and issues of parent-professional partnership in relation to VSSs. Definitions of key terms are provided. Experiences of using VSSs are also examined.

Chapter three: Methodology describes the theoretical framework, design, and methodology employed in conducting the study. The chapter explores participant recruitment, ethical considerations, procedures, and data analysis used in the study.

Chapter four: Data Presentation reports the findings of the study presented thematically through focus group and semi-structured interview data.

Chapter five: Discussion presents a discussion, analysis and interpretation of the findings. Data analysis methods are described and the results are presented. Limitations of the study are also discussed.

Chapter six: Conclusion, the last chapter of this thesis, consists of

discussion and conclusion sections for the study. Recommendations and implications for practice, as well as the researcher's reflections, are also highlighted.

References: contain a reference list of all the citations in this study.

Appendices: include relevant supplementary material highlighted in the thesis.

The third person point-of-view is used throughout the thesis. The words "the researcher" are used to reflect the views of the writer, a Speech and Language Therapist.

1.7. Summary

Having defined the common concepts within the thesis and given a rationale for the study, the following chapter presents a review of the literature relating to these concepts (Chapter 2). This is followed by the methodology of the study (Chapter 3).

2.0. LITERATURE REVIEW

2.1. Overview

This review considers the current literature pertaining to the topic of 'parent-professional collaboration' in reference to visual support systems (VSSs). In order to understand the way parents and professionals work in partnership and to apply this research to a current work situation, a systematic approach was used to search for the different views and findings of other researchers who explored the subject. This literature review provides the reader with definitions and discussions of key terms. The parent-professional model of service delivery, as well as research pertaining to changes in parents' and children's skills following the use of VSSs is also explored. The final section provides a discussion of the importance of studying the topic.

2.2. The literature search strategy

Literature searches were made using a systematic approach. Several academic health and education search engines were used. The Education Resources Information Center (ERIC), PubMed, and the National Database for Autism Research (NDAR) were the main source of materials. However, articles and journals were also found using web search engines such as Google Scholar. Particular search terms in the title, abstract and keyword categories of the search engines were entered. These included: parent-professional partnership, partnership, joint working, collaboration, collaborative working, cooperative, parental involvement, parent empowerment, family-centred care, integrated working, partnership and autism, family participation in early intervention, collective empowerment, early intervention in Ireland, visual support systems, visual aids, visuals, parent training, intervention for children with autism, parent perceptions, parent perceptions of visuals. The literature search was conducted throughout the whole duration of the thesis writing process to ensure currency and relevance.

References within references were also reviewed to obtain comprehensive information. Government websites, such as www.gov.uk and the Health Service Executive (www.hse.ie) were used to search for recent guidance and legislation concerning health and education issues. Guidance and legislation from both the Republic of Ireland and the United Kingdom were included to compare, contrast and provide up-to-date information if it was not evident in the Irish system at the time of this study. Other special educational needs were considered when literature pertaining to autism was not clear or inexistent. Both quantitative and qualitative research papers were included.

2.3. About *Autism Spectrum Disorder (ASD)*

2.3.1. *What is ASD?*

The most recent clinical description of ASD and the related diagnosis of *Social Communication Disorder (SCD)* (American Psychiatric Association 2013), includes difficulties to some degree with social communication and social interaction skills. People with a diagnosis of ASD also present with restricted/repetitive behaviour/interests, or non-compliant behaviour. See Appendix 1 for detailed diagnostic criteria. Previously, autism disorders were documented as separate subtypes, including *Autistic disorder*, *Childhood disintegrative disorder*, *Pervasive developmental disorder-not otherwise specified* (PDD-NOS) and *Asperger syndrome* (DSM – 4th Edition, American Psychiatric Association 1994). However, nowadays, the term *Autism Spectrum Disorder* is commonly used as an “umbrella” term to encompass the vast array of difficulties. The new definition of ASD indicates that people may present with mild, moderate or severe difficulties in the above mentioned areas and therefore there is wide degree of variation in the way it affects children (American Psychiatric Association 2013).

2.3.2. *Who is affected by ASD?*

ASD is a lifelong developmental disability with an estimated prevalence of 1 in 100 children in the United Kingdom (Brugha et al. 2012). There has been

an increase in prevalence over recent years, which may be explained by increased awareness and amended diagnosis criteria (Autism Speaks 2016). According to the NAS (2016), ASD is five times more common among boys than girls. Conversely, more recent research appears to suggest that these figures are due to girls being 'better at' camouflaging their symptoms (Dean et al. 2017). The exact cause of ASD is still unknown, however research appears to suggest that it may be caused by a combination of genetic and environmental factors influencing brain development (Gillberg 1998; Lauristen et al. 2006; Stromland et al. 1994). According to the NAS's (2016) website, ASD "affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them". It can be associated with motor coordination difficulties, attention difficulties and intellectual disability (Autism Speaks 2016; World Health Organisation 1993) making each individual with ASD unique.

2.3.3. How does ASD affect communication skills?

Some children with ASD are often described as being "verbal", whilst others "non-verbal". As the words imply, some may use spoken language whereas others may not. For those that do, their use of language may be delayed (NAS 2015) or they may present with social communication difficulties (Rapin 1997). Other alternative and augmentative communication methods exist for those with poor language skills (e.g. picture cards, sign language etc.). Communication is more than words (Sussman 1997). It "happens when one person sends a message to another person either verbally or non-verbally. Interaction happens when two people respond to one another – a two-way communication" (NAS 2017, p. 1). A high percentage of children with ASD demonstrate difficulties with interaction or social communication skills (whether verbal or non-verbal), which in turn can affect their behaviour. Social interaction is concerned with a person's yearning to connect with others (Royal College of Speech and Language Therapists (RCSLT) 2009). Individuals with ASD may: find it hard to answer appropriately when questions are asked, appear remote, demonstrate difficulties initiating

conversations or use socially appropriate conversation when talking to people (NAS 2016; RCSLT 2005). Whatever the difficulties, a number of intervention techniques are widely available to support communication development.

2.3.4. How are communication difficulties dealt with?

Interventions to support children with ASD typically begin after initial diagnosis. Multiple professionals often intervene by using a number of therapy techniques (based on the profile of the child). Parents and professionals are faced with a plethora of choices, and each member of the team may have differing opinions about which intervention technique is best to use. A discussion of how VSSs are selected as a therapy tool is presented in section 2.7.1. One of the ways in which communication skills can be supported, is through the use of a broad selection of visual therapy tools (Hayes et al. 2010). This is because many children with ASD are generally believed to have good visual processing skills (Schopler et al. 1995; Schuler 1995). There is a growing consensus that persons with ASD benefit from visual supports since most process most information visually (Hodgdon 1995; Gray 1998; Grandin 2006; Marcus et al. 2002; Mitchell 2009). Furthermore, improvements in the areas of behaviour and communication have been noted following the use of VSSs (e.g. Dalrymple 1995; Dettmer et al. 2000; Earles-Vollrath et al. 2006; Odom et al. 2003; Schmit et al. 2000). Increased visual acuity (Ashwin et al. 2009) and enhanced visual perception (Jolliffe and Baron-Cohen 1997; Shah and Frith 1993) has been reported in individuals with ASD. Dr. Temple Grandin, a prominent author and speaker on the subject of autism, provides a detailed account of her visual learning styles and describes how VSSs have helped her understand language more confidently:

I think in pictures. Words are like a second language to me . . . when somebody speaks to me, his words are instantly translated into pictures . . . One of the most profound mysteries of autism has been

the remarkable ability of most autistic people to excel at visual spatial skills while performing so poorly at verbal skills. (Grandin 1995, p. 19)

The claim that children with ASD have a preferred visual learning style is problematic. Learning style theories, such as Kolb (1984), and Jonassen and Grabowski (1993), do distinguish between different preferences learners might have, but also acknowledge that there can be significant variability among individuals. However, the concept of a different learning style has been challenged by researchers, such as Dekker et al. (2012), Howard-Jones (2014), and Dinham (2016), who believe that the idea of learning preferences is simply a myth and there is also a misconception around educators believing learning styles exist.

Assuming that all children with ASD have a visual learning preference is a bold statement. Although the literature provides a strong basis for the use of VSSs as an effective therapy tool due to this learning style preference (e.g. Gray and Garrand 1993; Kutter et al. 1998; Simpson and Myles 1998), limited research is available on parents' perceptions of what they feel works best for their child. Further research on visual learning preferences for children with ASD is also warranted, but goes beyond the scope of this study. According to Omrod:

Some cognitive styles and dispositions do seem to influence how and what students learn . . . Some students seem to learn better when information is presented through words (verbal learners), whereas others seem to learn better when it's presented through pictures (visual learners). (Omrod 2008, p. 160)

Experience has revealed that assessments carried out by professionals, such as Psychologists and Occupational Therapists, often report high scores in the visual skills area. Based on the researchers experience, as well as reports from colleagues and parents, it appears that some children with ASD

are likely to prefer a visual learning style. Parents often report that their child enjoys visual activities, such as looking at picture books, watching television, or paying particular attention to detail (e.g. at people or objects). What parents want is that their views are heard in selecting the right therapy approach so that intervention/education is tailored specifically to their child's needs (Pashler et al. 2008). Determining whether VSSs are indeed an effective therapy tool, from parents' perspectives based on changes they saw in their children, forms part of the scope of this research. The benefits of VSSs for both children with ASD and their parents are explored later (section 2.9.).

2.4. What are *Visual Support Systems* (VSSs)?

VSSs refer to visually presented therapy tools taking various forms, ranging from a picture (frequently referred to as “low-tech” devices) to an advanced computational system (“high-tech” device) (Shane et al. 2012; Still et al. 2014). They are often used by parents, and any professional working in the field of autism, to enhance communication and learning (Bernard-Opitz and Häußler 2011; Loring and Hamilton 2011). These therapy tools are “skill-based - facilitating development of specific skills through differing strategies” (RCSLT 2009, p. 10). VSSs were originally developed for students with ASD (Hodgdon 2001) but are now widely used in the area of special needs. The use of visual teaching strategies initially originated from the *TEACCH* (Teaching, Expanding, Appreciating, Collaborating, Co-operating and Holistic) programme. One of the concepts of this clinical and educational programme, created by Dr. Schopler in the 70s, is to structure environments/situations through the use of visual supports (Mesibov and Shea 2009). For example, providing a student with a list of visual instructions (such as pictures) when requesting him/her carry out an activity. Today, VSSs have mainly been used as therapy tools to support early intervention programs (Hodgdon 2001), as opposed to a therapy programme/approach per se. Therefore using these tools does not exclude other intervention methods.

VSSs are widely used as they have many advantages. They favour the visual learning style of most children with ASD, are easy to transport, relatively cheap (low-tech devices), accessible, and can be customized (NAS 2003). They can be used in any environment such as at home or school. VSSs have been given other names such as: *visual aids*, *visual supports*, and *visual strategies*. However, these all refer to the same concept. These systems can help children with ASD understand what they are required to do in unfamiliar or difficult situations, thus alleviating anxiety, frustration and potentially challenging behaviour (Gray 1993). Additionally, they can be used to enhance children's understanding of commands/expressions, promote social skills, or encourage verbal communication (NAS 2003). They also assist parents to communicate better with their child (Loring and Hamilton 2011). Although every child with ASD or *Social Communication Disorder* has unique strengths and needs, these therapy tools can be used with any child who has a diagnosis (NAS 2003). VSSs are therefore a skill-based approach to intervention; designed by professionals and parents to meet the individual needs of the child (Sicile-Kira 2004). Whilst research tends to focus on the benefits of using such therapy tools, barriers exist and these are discussed later in section 2.10.

2.4.1. What do VSSs look like?

The main types of low-tech VSSs include: tangible objects, photos, coloured images, line drawings, and/or written words. These can be presented in various forms such as: a timetable/schedule using a series of pictures e.g. for teaching toileting skills, or as a single symbol e.g. a laminated picture card used by a child to request for an item. *Velcro* can be used to secure pictures to a board/book. Plastic folders can be used to store pictures. Examples of how low-tech VSSs can be used include, but are not limited to: "picture timetables/visual schedules", "first/then" cards, "social stories", "Picture Exchange Communication System" (PECS), and single symbols used to encourage positive behaviour. These are defined and explained further in the

figures below:

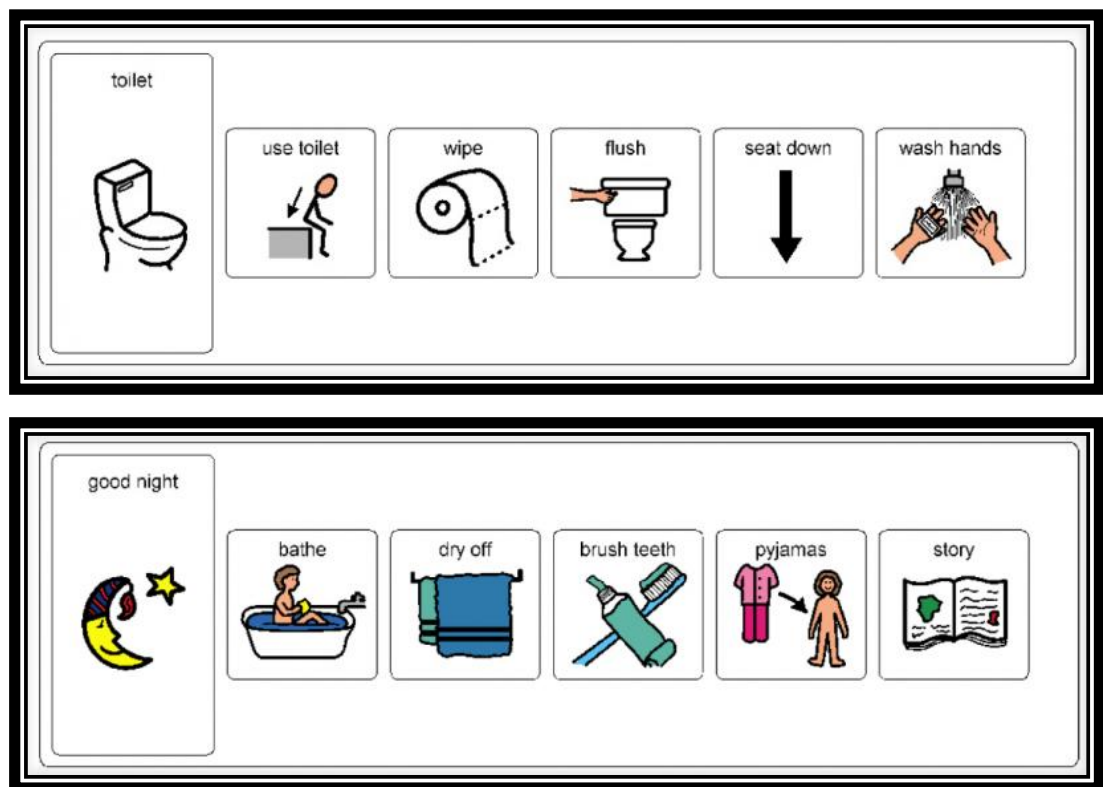


Figure 2. Visual schedule (2016). A visual schedule is a visual list of pictures/symbols used to represent what is happening (or what will happen) throughout a specific activity e.g. toileting, or throughout a child's day. The different steps involved are clearly presented, in temporal order, and broken down to encourage understanding of those steps, and also to reduce anxiety around routines. They also aid in the understanding of time, events, and places.



Figure 3. “First/Then” card (2016). *This therapy tool can be used with a child who is having difficulties understanding verbal directions. Therefore, for the child to understand that ‘first’ they need to do something (possibly less favourable) before getting something they want. In this case, blowing activity before getting the Ipad. The adult provides the child with verbal instructions together with the visual cues.*

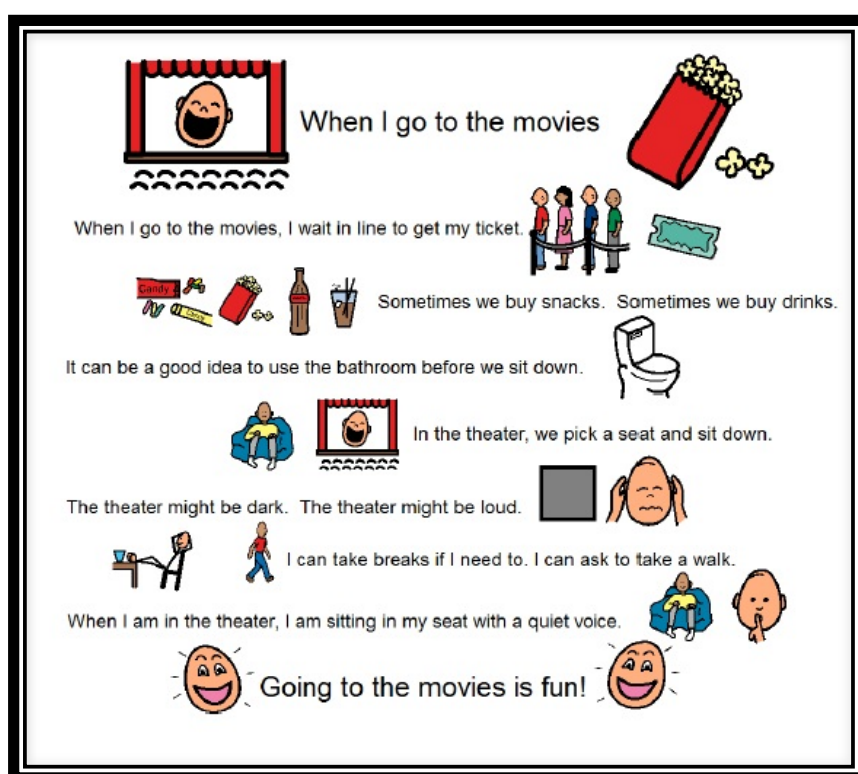


Figure 4. Social story (2016). *These are concise, written stories describing a particular situation, occasion, or activity e.g. going to the cinema. Originally developed by Carol Gray in 1991, they can also be used to teach social skills, such as playing with a friend. Pictures usually enhance these stories. Once a child can read and understand, the pictures can be removed. Social*

stories enable the child with ASD to understand what is expected of them in a particular social situation.



Figure 5. Picture Exchange Communication Book (2016). *This augmentative communication system was developed by Bondy and Frost (1985). Children are taught to communicate a need by exchanging a picture, thus helping to enhance the child's communication skills and understanding of the purpose of communication.*



Figure 6. Behaviour symbols (2016). *Symbols/Pictures can be used to teach positive behaviour skills. Verbal cues are given together with the visual cues, to help the child understand rules or approval.*

High-tech devices, such as a speech-generating device, are also considered to fall under the term “VSSs”. These are used as an alternative and

augmentative communication method to build language skills (see figure 7). Advantages and disadvantages of both high-tech and low-tech devices exist. For instance, low-tech devices are relatively cheap to make when compared to high-tech devices (Harris 2018). However, they can be impractical to use at times (De Leo et al. 2011; Hayes et al. 2010; Leroy and De Leo 2008). In selecting which device will be used, it is recommended that parents and professionals work together in this decision making process (Parette and Brotherson 2004; Parette and Hourcade 1997; Parette et al. 2000). Researchers such as Dugan et al. (2006) believe that further research in the process of selecting the appropriate device is warranted.



Figure 7. Dynavox (2015). *Purpose-built communication system with speech generating device.*

2.5. Parent-professional partnership: historical perspectives and recent approaches

The concept of “parent-professional collaboration/partnership” working in early intervention is in itself unclear, due to the quagmire of diverse definitions that exist (White 2002). Beveridge (1999, p. 130) for example, defines it as a “relationship in which there is full sharing of the unique expertise parents have in relation to their own children with the wider educational expertise . . . of professionals”. On the other hand, Blue-Banning

et al. (2004) include the idea of shared respect and authority. Despite differences in the definitions used, the underlying principles are similar. White (2002) summarises the main processes involved in most parent-professional partnership definitions. These are: 1) equal opportunity, 2) equal knowledge, 3) sharing information, expertise, knowledge, duties and responsibility, 4) shared purpose, 5) mutual respect, and 6) negotiation. The term can therefore mean different things to different authors and there is lack of clarity about its meaning. Adding to this muddiness is the use of various terms in literature when discussing partnership working (Percy-Smith 2005). Terms such as: partnership working, joint working, collaboration, collaborative working, cooperation, parental involvement, parent empowerment, family-centred care, and integrated working have been used interchangeably. In order to avoid confusion, the term “parent-professional collaboration” or “partnership” will be used throughout this thesis.

Attitudes concerning family participation in early intervention services have changed considerably during the past 50 years or so (Rosenbaum et al. 1998; Turnbull et al. 2000). A groundswell of developments in policy and legislation, research related to partnership working, and parent and professionals’ experiences, has had an effect on the models of parent-professional collaboration used within agencies. A variety of models of this parent-professional relationship have therefore been put forward affecting how the term is defined. These models, and the power relationships within these models are discussed in the next section below. Before that, it is the author’s belief that the selected use of terminology and model of working depends on factors such as: recent health or education government policy, background of the author(s) defining the terms, (for example whether from a health or education background), the terms used amongst the general public, and the personal and professional experiences of those defining the parent-professional relationship.

Whilst the term “professional” in this thesis has been used to encompass professionals from both health and education backgrounds, and whilst professionals from different backgrounds often work together within a partnership, it is important to note that the main focus of this study is partnership working within an early intervention service provided by the Irish Health Service Executive (HSE) (as opposed to education). The term “parent” has been used to refer to the child’s main carer. Further information on the structure of the selected organisation is provided in section 2.7. Although models of parent-partnership working in education can be applied to those in health, for the purpose of this study, literature relating to early childhood intervention and disability were mainly examined. Present developments in early intervention services for children with ASD have been towards parent-professional collaboration in planning and reviewing intervention. An overview of the progression of the way services have been delivered is provided below.

2.5.1. Counselling/Psychotherapy model

Classically, professionals were seen as “experts” with control over which goals would be focused on and how services would be delivered (Natiello 1990). Services were mainly delivered directly to the child’s mother, leaving the child with a developmental disability with reduced or no therapy input (Turnbull et al. 2000). Mothers were often seen as the ones who had caused the child’s “problems”. In this parent counselling/psychotherapy model, therapy services endeavoured to change a mother’s relationship with her child and the child’s diagnosis (Wolfensberger 1967). Power within this therapeutic relationship was “unequal, with the professional having power-over communication, resources, and outcomes” (Turnbull et al. 2000, p. 634). Interestingly, following research carried out on the causes of ASD, it is not surprising that from the 1950s up until the 1970s, mothers of children with autism were given the term “refrigerator mothers”. Children with ASD were seen as the product of mothers who were emotionless, detached and rejecting, thus depriving their children of the chance to form an attachment

with their mothers (Sicile-Kira 2004). By the 1970s, professionals' attitudes towards parent participation changed considerably and the parent involvement model began to be implemented.

2.5.2. Parent Training/Involvement model

Parents were encouraged to adopt the role of therapist at home, carrying out therapy programmes, and working on goals determined by the professional (Turnbull and Turnbull 1997). This parent training/involvement model continued to assume that the professional knew what was most appropriate for the child and that parents lacked certain skills (Turnbull et al. 2000). It was believed that parents needed to change their parenting styles in order to further develop their child's skills (Hunt 1972). Parents were therefore seen as students, learning skills to become their children's tutors (Turnbull et al. 2000). Professionals often saw parents who were unsuccessful at carrying out therapy programmes at home as being uncooperative (Bazyk 1989). The model assumed that parents did have the readiness to carry out the child's therapy programme, even if they wanted to assume the role of parent and not teacher. Additionally, the aim was to enhance the child's skills as opposed to parental outcomes (Turnbull et al. 2000). Despite some studies revealing that parent involvement did result in positive changes in the child's skills following the use of this model (Shonkoff et al. 1992), parents' goals and family's needs were not considered. Instead, parents were told what to do. More recently, however, there has been an improved appreciation of families' specific wishes and concerns, rather than just the child's (Rosenbaum et al. 1998).

2.5.3. Family-centered model

The family-centred model, introduced in the 80s and still widely used in paediatrics, focuses on the family making the final decision in relation to the needs of the child and the family. The family-centred model has been described as "a combination of beliefs and practices that define particular ways of working with families that are consumer driven and competency

enhancing” (Dunst et al. 1991, p. 115). Family-centred practice comprises of: 1) a focus on family strengths and resources as opposed to needs 2) encouraging family choice and power over required resources; and 3) the evolution of a two-way relationship between professionals and parents (Bailey and McWilliam 1993; Dunst et al. 1994). An equal partnership between parents and professionals is created. Support provided is adaptable and tailored to the family-identified needs of the child and family, with the family being the fundamental decision maker as to how services should be provided. The professional empowers the family to carry out their duties successfully (Dunst et al. 1988). This model encourages professionals to further develop families’ understanding of their and their child’s skills, to be able to make decisions about their child; organise a supportive social network; and empower parents to take decisions by offering a range of information and choices (Dokecki and Heflinger 1989). Work in the United States and health care services, such as the Institute for Patient- and Family-Centered Care (IPFCC) (2016, p. 1), provides the following definition:

Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families, and health care professionals. These partnerships at the clinical, program, and policy levels are essential to assuring the quality and safety of health care.

The IPFCC (2016) also considers several components necessary for an effective partnership including: mutual trust and respect, collaboration in the delivery of services, participation in decision-making, and complete information sharing.

Notwithstanding the move towards family-centred care, its achievability as a model of care has been questioned by authors such as Darbyshire (1994) and Coyne (2006). Young et al. (2006), who looked at the care between nurses and children in hospitals, found discrepancies between the priorities

of nurses and children's parents. Coyne et al. (2015) investigated health professionals' perceptions of family-centred care to which they found that professionals regarded working with children considerably higher than working with parents. Although this is not unpredicted given that individuals decide to work in paediatrics because they enjoy working with children, it is not consistent with a family-centred ethos, in which children and parents are treated as a single entity. Despite the model emerging in the 80s, a Cochrane systematic review of the family-centred care model (Shields et al. 2007), found no suitable findings, thus no decisions about its usefulness or suitability as a model of care can be made. Additionally, it has been criticised that this model assumes the family is unchanging and always present in the child's life, whereas the professionals working in the organisation(s) can change (Johnson 1990). Similar to the family-centred model is the 'Collective Empowerment Model' of service delivery and this is further described in the next section below.

2.5.4. Collective empowerment model

In the 1990s, the collective empowerment model began to emerge and is one that is continued to be used/recommended today. This model also takes into account families' priorities when planning goals and intervention (Turnbull and Turnbull 1997). In addition to what was described above in the family-centered model, it involves both families and professionals increasing their knowledge and skills over the supports required to attain mutually agreed upon results (Epstein 1995). It has been stated that this model:

. . . assumes power-through family-professional partnerships . . . It assumes 1) centrality of the family, 2) family choices as the basis of decision making, and 3) family strengths and capabilities as the focus of intervention. The major additional assumptions within a collective empowerment model focus on 1) access to resources, 2) participation, and 3) changing community ecology. (Turnbull et al. 2000, p. 642)

Power-through partnerships involve families and professionals working together in a creative manner, to reach mutual objectives by sharing decisions, collaborating, and having a good relationship (Turnbull et al. 2000). It involves all participants (clinicians and families) increasing their abilities and skills in order to achieve these objectives (Epstein 1995; Pinderhughes 1994). Power is shared and the roles of professionals and families are equal as opposed to arranged in order of rank (Prestby et al. 1990). Other advantages of this model include: synergy (Bond and Keys 1993) and increased self-satisfaction for all those who participate in the partnership (Natiello 1990). Equal involvement occurs from the start of a planned undertaking, right through completion of that project planned to achieve a particular aim (Whitney-Thomas 1997). Turnbull et al. (2000) discuss how it is inadequate to involve families after goals have been planned and determined by professionals. Genuine, shared involvement occurs from the beginning with both families and professionals contributing equally to the characteristics of the project. Numerous barriers to working with parents have been described in literature. These mainly focus around poor communication between partners, lack of an understanding of how the model should work, and contradictory opinions resulting in unequal perceptions of partnership working (Blue-Banning et al. 2004; Hopia et al. 2005; Shields and Coyne 2006). Issues with the collective empowerment model of service delivery specifically related to VSSs are discussed later in section 2.8. Therefore, only by recognising, understanding, and working on the dissimilarities in perceptions between parents and professionals can successful parent-professional partnership be achieved (Shields 2010), adding value to the purpose of this research study.

2.6. The role of professionals in developing effective partnerships

The first step to partnership working is for both parents and professionals to recognise that working in partnership is beneficial and that people can accomplish more by working together rather than working alone (Dhillon 2005). The idea that professionals and parents work together signifies that

more skills are gained by everyone involved in the partnership, which ultimately improves service delivery (White 2002). Shared responsibilities and equal power encourage people's skills to be valued and are essential to an effective partnership (Wildbridge et al. 2004). Sloper (1999) suggests that each partner should value the thoughts and feelings of the other and allow them to express these, as well as include them in decisions and provide them with information. However, whilst literature recognises that an effective relationship between parents and professionals promotes partnership (Keen 2007) the way in which that decision is put into practice and the style of the professionals' interactions can often be challenging. Common challenges are discussed later in section 2.8.

There have been some studies based on the experiences of parents working in partnership with professionals that highlighted the benefit of understanding what is required when working with parents. According to the fourteen parents studied in a research carried out by Pinkus (2005), four principles are required when forming successful partnerships. These include: 1) clarity of the roles and responsibilities of the partners; 2) clarity as to who is involved in the partnership; 3) empowerment amongst partners; 4) transparency in special education procedures. In order to create a successful partnership, Pinkus (2005) recommends that the roles and responsibilities of the partners are defined, that power is shared equally amongst partners and that the persons responsible for meeting the needs of the child are identified. Furthermore, Park and Turnbull (2001) looked at the experiences of Korean-American parents of children with special needs to determine their experiences when working in partnership with various professionals. From their semi-structured interviews, they found several factors that affected the way parents and professionals worked together. These included interpersonal factors, such as respect and trust; structural factors, such as flexibility and caseload; and cultural and linguistic factors, such as information and advocacy. Some of these factors are examined in more detail below.

2.6.1. Mutual respect, trust and honesty

Respect, trust and honesty must be shared between parents and professionals (Labonte 1994). In order for this to develop, partners must appreciate each other's thoughts and value their beliefs so that shared objectives can be achieved (Dunlap and Fox 2007). Although professionals are often under pressure when deciding how to convey information to parents (Bruce and Schultz 2002), it is important that communication factors are taken into consideration. Professionals must therefore use familiar terms and explain any concepts that parents may not understand (Flett et al. 2001). This can often reduce the perception of threat (Bruce and Schultz 2002). It is important to consider that having a child with ASD can severely disrupt family life and therefore employing VSSs in the home environment can place additional strain on families (Hayes et al. 2010). Parents may experience stress, anxiety, fear, and guilt (Gray 1994) and therefore these emotions need to be considered as a typical experience for parents (Bruce and Schultz 2002). To that end, it is important that a partnership is created where parents feel like they can trust and respect professionals. Skills that professionals can use to facilitate the development of a partnership include empathy, respect and genuineness as discussed by Rogers (1980) cited in Hornby (2000). These characteristics do not develop immediately and since all parents and families are different, time must be set aside to develop a relationship with the family (Keen 2007). Using this approach will form the basis of a good relationship with parents and in this way parents are less likely to feel judged (Bruce and Schultz 2002).

2.6.2. Shared planning and decision-making

Keen (2007) suggests that parents should be seen as part of the decision-making process as opposed to simply treating them as "clients". For this to happen, Gallant et al. (2002) suggest that partners come together, share their knowledge and acquire skills from each other so that a positive relationship can be developed. However, research suggests that rather than power-sharing with professionals, parents have often felt they had to struggle

in order to be heard (Keen 2007). As a service determined to meet the demands of the family, it is important for the professionals to understand that when one partner takes on more power, the partnership generally fails (Morrow and Malin 2004). Although Gallant et al. (2002) acknowledge that power-sharing may be difficult to achieve, in order to avoid conflict there should be open communication between parents and professionals to prevent professionals drawing conclusions before listening to parents' views (Pinkus 2005). This allows for a better working relationship as parents may feel more comfortable communicating important information to professionals and vice versa (Pinkus 2005). Dunlap and Fox (2007) also suggest that when planning goals, the family system should be involved and all characteristics of family life should be considered. Keen (2007) emphasises that the parent-professional partnership will face difficulties if professionals do not recognise this active family system and understand how to support both the individual and the family.

2.6.3 Defining roles and responsibilities

It has been identified that the role of parents is to participate as equal partners in the education of their child with special needs (Report of the Commission on the Status of People with Disabilities 1996). However, professionals are undoubtedly fully aware that putting these policies into practice can be intricate and therefore calls for perseverance (Todd 2003). In order for partnership to be effective, each partner must understand each other's roles and situations (Dunlap and Fox 2007). Pinkus (2005) found that parents and professionals failing to define their roles is one of the most common barriers in implementing parent-professional partnership. In order to be able to discuss such issues, professionals are required to communicate effectively and openly with parents (Dunst 2002). However, Rodd (1998) identifies that early childhood professionals have little training regarding the skills required to work effectively with parents. In order for parents and professionals to define their roles and responsibilities, it is important that

professionals are provided with the appropriate training to be able to communicate effectively with parents (Ebbeck and Waniganayake 2003).

2.6.4 Working as equal partners

Another component of parent-professional partnership is the concept that parents are “perceived as having equal strength and equivalent expertise” (Wolfendale 1985, p.14). However, working with parents as equal partners can often be challenging, as professionals may feel that boundaries are being crossed (Edwards 1999). White (2002) suggests that this will not occur if the partners keep the purpose of the relationship in mind. Professionals may also assume that parents are not ready to take on board certain information or might not be in a position to make decisions (Freitas and Shelton 2005). This assertion can be observed in a study carried out by Fylling and Sandvin (1999) where teachers felt it was their responsibility to develop an individual education plan for the child. Conversely, parents expressed that teachers did not appreciate their opinions. Although this example is relevant to education, this situation can be applied to early intervention services. When factors such as time constraints and personalities are taken into account, the process becomes more difficult (Russell 2004). Difficult or not, early intervention services that succeed in engaging families to work in partnership should embrace a philosophy of partnership where power and responsibility are shared (Henderson and Mapp 2002).

The concept of power and shared responsibility can also be questioned amongst professionals. One question that arises is whether attempting to empower parents, disempowers the complementary professionals. Experience indicates that at times professionals are left feeling content with the way they work with other professionals. Instead, working with other professionals can leave one feeling confused, upset and possibly angry. Previous research has observed the collaboration between general practitioners and other health professionals. Disagreements and clashes

over roles and responsibilities, and an absence of shared planning and decision-making insinuate that power issues are significant factors in the relationships between professionals and influence the way professionals work together (Kirby et al. 2008; Shortus et al. 2007). Additionally, how parents perceive professionals in terms of professional status can also affect the way the partnership works. In a study carried out by Davis et al. 2007, patients were more willing to ask doctors factual questions as opposed to nurses, with the researchers suggesting that patients may view doctors as an essential resource for such information when compared to nurses. Experience has also demonstrated that parents of children with autism, within the context of this study, were more likely to follow the recommendations given to them by a Child and Adolescent Psychiatrist as opposed to those of a Speech and Language Therapist. The reason for this could be to do with parents viewing some professionals as 'more important' than others.

2.7. Collective empowerment model, for children with autism, in the Republic of Ireland

The aim of autism early intervention services within the HSE in Ireland is to provide a comprehensive, family-centred and specialised service to children with autism and their families (HSE 2012). The service being studied, available to children aged 6 years or under, is based on the principles of family-centeredness and collective empowerment. With the advent of parent-centred practice and legislative changes in the Republic of Ireland mandating the importance of parent involvement when dealing with young children's special educational needs (Department of Education and Science 1998), professionals have been encouraged to work closely with parents and families (National Council for Special Education 2006). The historical context of the development of early intervention services within the Irish health organisation is presented to provide the reader with an understanding of this evolution.

In the 1970s early intervention services for children with disabilities were affected by organisational reconfiguration. Governmental and the community's concerns followed a move towards smaller community settings as opposed to large institutional care (Quinn and Redmond 2005). In 1990, *The Needs and Abilities Report* (Government of Ireland 1990) highlighted the need for multi-disciplinary, specialist early intervention services to work with parents. Providing all parents with information, support and concrete guidance was emphasised. The purpose of early intervention services, which to some extent mirrors the parent involvement model was:

- (a) to assist the parents to cope with the trauma of having a child who is developmentally delayed;
- (b) to facilitate the acceptance of the child by parents and siblings as a full member of the family;
- (c) to prevent the subsequent development of secondary disabilities (physical/emotional);
- (d) to offset the delay in the development of these children by systematic teaching and training programmes and by guiding the parents in how best to nurture the child's progress.

(Government of Ireland 1990, p. 21-23)

During the second half of the 20th century, autism early intervention services in the form of community clinics were set up following the expressed need. Services were provided to children, their families and the schools they attended. In the 1990s there appeared to be an assumption that all parents required a certain level of support. However following *The Needs and Abilities Report* (Government of Ireland 1990), *The National Children's Strategy* (Department of Health and Children 2000) emphasised the need for professionals to view the child as a 'whole', whilst also recognising that parents know their child best and should have a say in the way services are delivered. Health and education policy was later presented in the *Disability Act* (National Disability Authority 2005) giving the right to children with

disabilities to have a health and education assessment of need, whilst also determining appropriate planning. Later in 2009, a national programme was introduced, based on the recommendations of the *Report of the National Reference Group on Multidisciplinary Services for Children aged 5 - 18 Years* (Health Service Executive and National Reference Group 2009), advocating a family-centred model of service delivery. The *National Framework for the Delivery of Early Intervention Disability Services* (HSE 2010a) was also developed to support this model and emphasises the inclusion of parents and their views. In 2010, the HSE launched a national programme: *Progressing Disability Services for Children and Young People* (HSE 2010b), in joint partnership with non-government agencies, the Department of Health and Children and the Department of Education and Skills. New structures for disability services were introduced to provide geographically based services, to work in partnership with parents by considering the families' needs, and for multi-agencies such as health and education to work together. This programme was not fully implemented at the time of this study. Whilst a family-centred model of care was implemented, the autism service under investigation was not yet reconfigured at the time of study. Additionally, when the study was carried out no national policy for specialist Early Intervention services was present. However, in 2015, a *National Strategy on Children and Young People's Participation in Decision-Making (2015-2020)*, developed by the Department of Children and Youth Affairs, focused on giving children and their parents in early years services a voice in decision-making.

2.8. Description of service under exploration

The service under investigation provided services to children aged up to 18 who had a specific diagnosis of ASD without any significant intellectual disability. The service was divided into early intervention services (children under 6 years of age) and services for school-aged children. Most of the children attending early services attended pre-school or nursery. The early intervention service was explored during this study. The service covered three main regions in the country. Services provided included:

- Training for parents and other professionals.
- Support groups for parents and other family members.
- Direct clinical support to children and their families accessing the service.
- Clinical support in various environments such as home, school and clinic.

To access services, a referral form, a copy of the diagnosis of ASD, and a psychological assessment was required. Both parents and/or professionals could refer the child into the service. Access was also dependent on geographical area and the age of the child. Whilst access to services was beyond the researcher's control, admission into specialist early intervention services has been described as a traumatic and anxiety-evoking experience for families (Foran and Sweeney 2010). Following receipt of the required paper work, an intake meeting with various professionals took place where referrals were considered by the team and accepted if the child met the criteria. At times, following entry into the service, a waiting list for service delivery was present.

In terms of the model of practice, a variety of team working models were used historically throughout the service. At the time of study, a trans-disciplinary model of care was mainly used. This involved more than one professional working with the family, sharing information, learning together and seeking to work beyond traditional professional boundaries (Soan 2004). The aim was for various professionals and parents to work together by means of sharing values, combining efforts and developing close relationships, which allowed realistic recommendations to be agreed upon (Klin et al. 2000). Whilst it was believed that the service worked hard to provide a trans-disciplinary model of care, whether this was indeed evident is hard to measure. Additionally, most policies and guidance in the Republic of Ireland fail to use the word 'trans-disciplinary', but rather 'multi-disciplinary'. Experience revealed that professionals endeavored to provide a trans-

disciplinary model of care. Professionals were encouraged to ‘think outside the box’ due to funding constraints. Despite the model of practice, service provision was essentially personalised according to the needs of the family and child (HSE 2010a). To understand the team structure, Katzenbach and Smith’s (1993, p. 41) team definition was used: “A team is a small number of people with complementary skills who are committed to a common purpose, performance goals and approach for which they hold themselves mutually accountable”.

The team composition comprised approximately 5-7 disciplines and included a: Speech and Language Therapist, Clinical Nurse Specialist, Occupational Therapist, Social Worker, Behaviour Specialist, Child Psychiatrist, and Educational Psychologist. The organisation consisted of two main management levels: line managers for each discipline and a director of service, overlooking the whole service. A team map, developed by the researcher, can be seen in Figure 8:

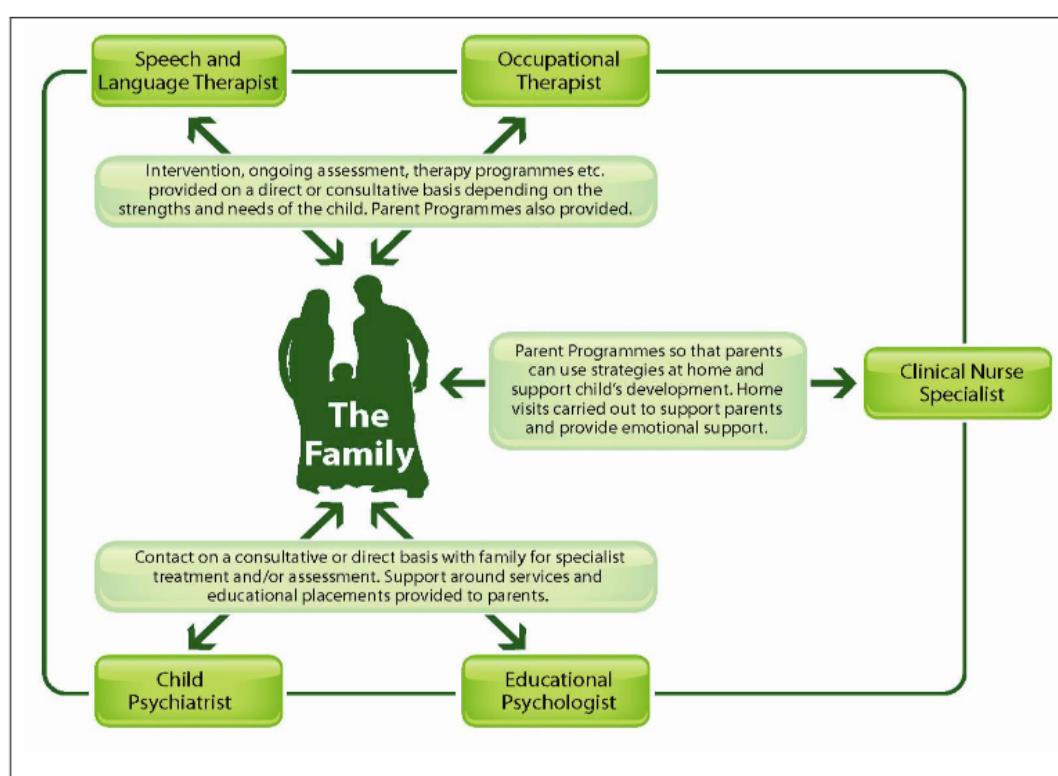


Figure 8. Team map.

From the researcher's perspective, whilst team dynamics and effectiveness has not been assessed throughout this research, the team worked well together. In general, despite some occasional conflict, where old ways of working clashed with new ones, most staff reported high levels of team satisfaction. This is possibly reflected in the number of years most professionals remained working for the service.

2.8.1 Setting goals and determining service provision: how is the need to implement VSSs and support parents identified?

Services for children with autism aim to use the concept of shared decision-making and goal-setting when planning intervention. In Ireland, there is a national strategy for families and professionals to collaborate during the goal-setting process (HSE 2008; Department of Children and Youth Affairs 2015). On entering the service, an individual care plan for each family attending the service is developed. This care plan process involves observations of the child, discussions and interviews with parents to identify areas of strength and need. Collaboration and dialogue is used to establish goals for intervention and a plan of action. Measurable, attainable and client-relevant goals are developed together (Department of Health and Children 2007). The service recognises that the decisions family make depends on their resources, concerns and priorities. The role of the professional is therefore to support the family to make these decisions based on the family's strengths and resources. The family's decisions are always respected.

As regards identifying VSSs as a goal or as a technique for meeting goals, this is decided in partnership with the family. Supporting parents to implement these tools is generally carried out via several strategies such as: group training, written information, discussions, home visits, opportunities to practice, and demonstrations/modeling. Again, how support is delivered is decided in partnership with the family and is based on the family's needs. Service is designed to be flexible and responsive to the families' identified strengths and needs. The aim is for the family and intervention group to pool

resources and ideas thus increasing satisfaction for those who participate. See Appendix 2 for an example of a care plan discussion.

2.9. Issues with the collective empowerment model when determining goals and service provision around VSSs

To this point, parent-professional partnership working and the characteristics required for an effective partnership have been explored. The aim of how a service operates has also been discussed. Whilst a collective empowerment model of service delivery is an aspiration for most service providers and users, its interpretation is highly dependent on the participants' beliefs and expectations (Harry 1992). Thus certain challenges cannot be ignored.

Despite the acknowledgement of the need to involve parents when deciding on goals and service delivery, professionals and parents have reported difficulties with this model (Hodge and Cole 2008). The beliefs and expectations between parents and professionals may not be shared collectively and therefore different goals and intervention techniques may be identified (Case-Smith 1993; Lake and Billingsley 2000). Ward (2009) found that parents were not involved in goal setting on entering a service, leaving the professional to determine the goals themselves. Notwithstanding the evidence base and advantages of using VSSs, on entering the service, parents have often reported that they do not feel comfortable using these therapy techniques. Reasons such as "I don't want to use visual supports because I don't want my child to look different" have been expressed. Whilst informal assessments, to determine whether VSSs are required in order to acquire target skills are available, no standardized measures exist and it is usually through clinical judgment, observations and discussion with parents that the need to use these therapy tools is determined. Conversely, it seems reasonable to assume that professionals may find time constraints and large caseloads do not allow for much collaborative dialogue with parents (Stahmer 2006).

For example, a goal for parents of a young child with ASD who is non-verbal might be for him/her to talk. An intervention might be the use of a Picture Exchange Communication System (PECS) (see Figure 5) to enable the child to develop their speech. Such an intervention does not work directly on the child's ability to use words but provides the child with an understanding of communication, which is important before actual speech develops. It is difficult to "convince" someone to use an evidence-based technique if they have never heard about it or if they have already formed negative opinions of the intervention technique. Some parents are very articulate about the goals they want their child to achieve, others are more unclear, and some demonstrate little awareness of what they want their child to achieve. The aim of the professional is to facilitate the process of identifying potential goals through the use of questions and comments. The professional listens and together SMART (Specific, Measurable, Attainable, Realistic and Timely) goals are written down. But what happens when parents and professionals disagree? Or when the parent does not feel empowered enough to take these decisions? Did the parent appear apathetic, resulting in the professionals "having to" take the decisions? Do parents want to develop goals on entering a service? Professionals, such as Speech and Language Therapists, are trained to identify therapy goals to work on (RCSLT 2009). Some professionals may still feel that they should be the ones to hold the final decision around which goals will be tackled (Giangreco 1990; Winton 1996).

Following the identification of goals, parents and professionals work together to decide how the goals will be achieved. The implementation of VSSs in the home and clinic environment is decided with parents. For example, a child might have a goal to use a visual schedule during his/her morning routine to promote attention and cooperativeness (see Figure 2). As regards a plan of action, the parent and intervention team might decide that parenting help is offered so as to achieve this goal. Interventions are provided as a team or as a single discipline, based on the needs of the family and resources available.

Using a collective empowerment model of service delivery when determining service provision also presents several challenges. As a professional working in the field, one must admit that determining service delivery with parents around VSSs can sometimes be based on a traditional authoritarian power relationship. Unfortunately, professionals' decision to use the above method can be based on difficulties such as sharing power, time and resources available (Stahmer 2006), background training (Turnbull et al. 2000), and even recommendations in literature. Additionally:

. . . the power differential that exists between practitioners and their clients . . . has too often been exploited by practitioners who intend to engage clients but who instead meet their own needs for personal power and esteem through the intervention process. (Pinderhughes 1994, p. 27)

The idea that spending time to develop a relationship with parents, so that their ideas can be elicited, is sometimes viewed by professionals as not constituting “real work” (Lawlor and Mattingly 1998). Recent guidelines do recommend that professionals train and support parents to use such therapy techniques so that they can use them at home with their children, thus minimising difficulties (HSE 2012; National Research Council 2001; RCSLT 2009). Additionally, professionals are generally trained to work with children rather than their families (Bailey et al. 1992), which may suggest why they choose to use this model.

From a professional's viewpoint, satisfaction with the parent training model may therefore relate to the idea that parent involvement will improve outcomes for children. Studies have demonstrated that supporting parents to use VSSs results in improved outcomes for children. For example, supporting parents to use PECS¹ via explanation, modeling, practice and feedback, with 90% accuracy, resulted in positive effects on their child's

¹ PECS is a visual support system used to encourage communication. See Figure 5.

communication skills (Ben Chaabane et al. 2009). Also, supporting parents to use a visual schedule², following feedback in the home environment, revealed improved behaviour and social interaction skills for the children (Krantz et al. 1993). Parenting programmes, such as the *More Than Words* parent programme (Sussman 1999), which also includes teaching parents to use VSSs via group training and home visits, resulted in positive effects as regards to children's communication skills (Carter et al. 2011).

Although such studies indicate that the parent involvement/training model can lead to improvements in the child's acquisition of skills, these studies tend to neglect the effect training has on families. Additionally, they fail to talk about whether support was a priority for families in the first place and generally consider parents to be a homogeneous group (Turnbull and Turnbull 1997). Often, parents do not want to take on the role as "professional" but prefer to be "just" parents (Seligman and Darling 1997). It is important to recognise that parents know their child best and therefore professionals should view the collaborative process as one in which parents and professionals decide on goals/service delivery together (Turnbull et al. 2000). The parent training model tends to assume that parents lack the necessary skills to use and implement VSSs and therefore parent training is needed for parents to become effective teachers. It assumes also that parents have the time and energy to be implementing VSSs at home. For parents to implement VSSs, means they must balance this demand with other demands in their daily lives (Llewellyn 1994).

However, it is not safe to assume that this model is used only because it meets the needs of professionals. On entering an early intervention service, parents often need and want help to actively support their child's skills (RCSLT 2009; Trevarthen 1998). Experience has demonstrated that sometimes parents favour a parent training model of service delivery. This may be because parents want information on the efficacy of autism-specific

² A visual schedule is another type of visual support depicting a series of activities. See Figure 2.

therapy tools, as well as supplementary information that will help them to determine whether a therapy tool is in fact suitable for their child (Simpson 2005). Another reason may be because parents feel they want professionals to tell them what needs to be worked on. Indeed the benefits of training parents of children with autism to use therapy techniques have been well established. For example, parents feel more supported (Moes 1995), less stressed and satisfied with the quality of training delivered (Koegel et al. 1982). However, researchers such as Turnbull et al. (2000) argue that parents' satisfaction with this training model may be because they are not aware of other partnership models of service delivery other than the professional being the expert. Therefore, if questioned, parents may respond that they are satisfied with the parent training model.

Additionally, research has suggested that parents differ in their ability to state their concerns and beliefs (Case-Smith 1993). Parents may state that they do want to use VSSs, even if they do not really or vice versa. They may have been told that if they do not use VSSs, their child would not progress. This may explain why they choose VSSs as part of their child's intervention plan. Experience and research suggests that parents may also feel confident to state that they want to work on VSSs with their child, and yet they may not follow-through with activities as agreed (Dinnebeil and Rule 1994; Lawlor and Mattingly 1998). Although parents may choose to implement VSSs, they may still feel that their main concerns were ignored by professionals (Fyffe et al. 1995).

Research in the area of parent-professional collaboration has tended to focus on involving parents and recognising family priorities when devising goals, as opposed to involving families in other aspects of therapy (Winton 1996). Winton (1996) explains that following the identification of goals, professionals still tend to decide which intervention strategies will be used to achieve them. It is the author's belief that this sometimes happens because professionals feel parents may not have heard of VSSs before. It is acknowledged in

family-centred practice that professionals provide parents with information around effective therapy techniques so that ultimately they can take informed decisions (Law et al. 2003). However, discussing intervention strategies with parents who have children with ASD can sometimes feel like one has to be a good “salesperson”. Research has demonstrated that recognising a particular intervention technique can be a confusing task for parents given the variety of choices available (Hart 1995). VSSs do not typically fall under “name-brand” approaches carried out by studies, researched by most parents or even recommended by all professionals, contrary to techniques such as *Applied Behaviour Analysis*³ (Lovaas 1987; McEachin et al. 1993). Unfortunately, sometimes parents of children with ASD invest in therapy techniques only if they are promoted well, even if little evidence supports them (Celiberti and Lorelli 2013). One questions whether using a family-centred approach, where parents are meaningfully involved in planning goals and intervention (Trivette et al. 1996), is necessarily the right thing to do.

Despite the barriers, evidence of partnership working when determining goals has been reported (Carroll 2011; Whyte and Kelly 2009). Bailey (1987) argues that professionals should not attempt to force their beliefs on parents, but rather should work together with parents to determine goals and achieve a mutually satisfactory plan. Choosing one parent-partnership model of service delivery may not always satisfy the needs of parents and professionals throughout the relationship journey. An amalgamation of approaches may also be evident, based on the needs and resources of the family. It is therefore recommended that the professionals “reflect on their partnerships with families and ensure that families truly have choices in how these critical relationships evolve” (Turnbull et al. 2000, p. 646). Hence, an added reason for carrying out this research study.

³ *Applied Behavioural Analysis* refers to the use of the principles of learning from Behaviour Analysis, and the methods and skills resulting from those principles, to the resolution of difficulties of social importance (Center for Autism and Related Disorders 2018).

2.10. Changes in parents' and children's skills

As mentioned, children with ASD demonstrate difficulties with communication, social interaction skills, as well as behaviour. This presents as a challenge for most parents, and therefore using an approach that helps to manage such difficulties is an understandable route for early intervention services. Research concerning the effectiveness of using VSSs in terms of the benefits for both children with ASD and their parents is another objective of this literature review. The field of ASD remains debatable, with a number of problematic claims for efficacy of therapies (McConachie and Diggle 2002). The evidence for using VSSs however, is robust and developing (Dettmer et al. 2000; Ganz and Simpson 2004; Charlop-Christy et al. 2002). Volkmar et al. (2014), in their review, state that there is evidence for the effectiveness of some VSSs. The reasoning behind VSSs is also reflected in books, such as Goldstein and Naglieri (2013). Numerous articles have been written comparing the outcomes of different VSSs. However, the evidence is still questionable.

Odom et al. (2003) reviewed 37 studies, carried out between 1999 and 2002, to identify effective intervention approaches for young children with autism. Efficacy was established through peer-reviewed articles in journals using single-subject design studies. Most studies used multiple-baseline experimental designs and contained approximately four replications of treatment effects. At least 50% of the participants in the studies had a diagnosis of autism and were under 6 years of age. Remaining participants had other disabilities. Visual supports were recognised as an intervention approach used with children with autism. In terms of empirical support, visual supports were found to be effective as measured by the number of studies that supported the practice when compared to other intervention approaches. However, the authors recognised that the evidence collected was limited.

Research concerning the affects VSSs had on children with ASD (particularly language, communication and behaviour) was also considered for this

literature review. The effect of a VSS on three children with ASD, to reiterate what happened during their school day, was examined by Murdock and Hobbs (2011). A multiple-baseline design across students was used. Pictures and text were used and participants were encouraged to respond to the prompt “tell me what you did in school today?”. Participants demonstrated an increase in the amount of events they were able to retell. The study demonstrated large effect sizes and positive social validity. In another multiple-baseline design study carried out by Murdock et al. (2013), four young children with ASD used an iPad play story to increase their pretend play skills. Video clips were utilized showing toy characters producing scripted character dialogue. Three of the four participants demonstrated increases in pretend play skills with non-overlap of all pairs analysis revealing moderate and strong effects across intervention phases. Effects were for the most part maintained during generalization opportunities with peers and during a 3-week follow-up condition.

However, very often, research on the benefits of using VSSs tends to ignore parents’ perceived quality and quantity of change in their children’s skills. After demonstrating the importance of including families’ views, it is self-evident that these should be considered. Research concerning parents’ use of VSSs is growing (e.g. Ben Chaabane et al. 2009; Kashinath et al. 2006). One study carried out by Krantz et al. (1993) explored parents’ use of a visual schedule in the home environment. The parents of 3 boys with autism were taught to use visual, activity schedules to promote increased independence at home. A multiple-baseline across subjects revealed that the behaviour and social interaction of the children improved. Although parents also reported positive changes in behaviour, the study does not examine parents’ views on using the therapy technique. This concept is explored in more detail in section 2.10.

2.11. Parents' experiences of using Visual Support Systems

The researcher's experience using VSSs with parents and children indicates that they are an effective therapy tool. Although objective data regarding the experiences of parents using this approach is currently limited, parents' perceived understanding of different topics, and perceived confidence and ability to use other therapy techniques have been examined in a variety of studies. For example, studies regarding parents' perceived knowledge of a topic or intervention technique following training have shown that parents often report an increase in understanding (Ingersoll and Dvortcsak 2006). In studies, such as those carried out by Keltner et al. (1995) and Llewellyn et al. (2003), significant post-intervention differences were noted between intervention and no-intervention comparison groups in terms of parents' knowledge following training. Conversely, studies that have investigated parent perceptions of behavioural techniques reported greater confidence and ability to use these strategies with their children following training (Dillenburger et al. 2004; Pisterman et al. 1992).

Most of the above mentioned research however tends to focus on measuring attitudes through the use of scales and tests as opposed to generating in-depth and rich information regarding parents' perceptions. Alternatively, most qualitative studies on parents' perceptions tend to focus on other parent opinions for instance, perceptions of parent-professional relationships, experiences of training programmes, and parental involvement in education (Baker 1997; Clondalkin Partnership 2006; Stoner et al. 2005) as opposed to VSSs. What seems clear is that more research is needed in the area of VSSs (Rao and Gagie 2006) and therefore understanding parent's perceptions should provide ways for refining practice (Baker 1997).

Although VSSs can be beneficial, certain difficulties often hinder their use and potential for improving children's skills. Following a literature search, some documented disadvantages of using VSSs were located. Hayes et al. (2010), in their formative work exploring the use VSSs, have reported that

creating and using VSSs can be challenging in relation to resources, particularly time. They go on to describe how using traditional low-tech devices, such as visual schedules, can be a strenuous task. Creating small pictures is a very time-consuming and laborious process making them a hindrance. Other difficulties reported included:

- Ensuring that the VSSs are designed to support a child's communication skills based on their age and strengths.
- Ensuring that they meet the needs of the child, which may change frequently.
- Managing and creating the large amount of pictures used.
- Using devices such as cameras, printers, laminating machines to create pictures.
- Keeping pictures up-to-date.
- Struggling to find appropriate images.
- The requirement of training from professionals.
- Keeping and having space available for a large amount of pictures.
- Having to keep more than one copy of the picture cards.
- High-tech devices can be inflexible and expensive.
- Making sure they are flexible and adaptable.
- Making the student "stand out".

Although the study reports that data was collected from caregivers and professionals, the article fails to report whether the parents specifically stated the above concerns. Observation and experience of the authors appears to dominate most of what is said in the article and therefore parent's perceptions are not reported directly. Another interesting point that Hayes et al. (2010, p. 675) make however, is that the "push for assistive technologies, such as visual supports, is often thought of primarily from the perspective of the individual with a disability, a position that tends to overlook the needs of the caregiver". Due to the added stress that families have coping with the fact their child has a diagnosis of autism (Dunn et al. 2001; Lecavalier et al.

2006), it is vital that professionals are aware of parents' situation and therefore work in partnership with them when deciding on and implementing VSSs (Dawe 2006).

2.12. Conclusion

If VSSs have been identified as a goal together with parents and we provide parent help based on parents' priorities, then we can confidently state that the partnership model is based on family-centeredness. Unfortunately, whilst professionals and parents may favour the concept of partnership working, evidence in practice requires examination (Cheminais 2009). The collective empowerment model therefore recognises that parents "choose to participate at different levels, at different times, and in different ways" (Turnbull et al. 2000, p. 644) so that the use of VSSs is based on family choice as opposed to professionals. Although research has investigated the effectiveness of professionals supporting parents to implement VSSs, effectiveness is frequently measured through the use of standardised and validated instruments. There is therefore less research on the qualitative aspects of effectiveness as seen through a parental lens. There is a paucity of information on how parents feel about the support they received. Also, whether they feel that they and their child have changed following the support. One rationale for this research is therefore to address this gap in the published literature and add to as well as compliment research on the effectiveness of supporting parents of children with autism in the use of VSSs.

Inclusion of parents' views in the evaluation of parent support is important for a variety of reasons. Parents generally have the main responsibility for and influence over their child's development, and their opinions concerning success and/or failure should be considered noteworthy (Bernheimer et al. 1990; Guralnick 1989). Understanding parent views (positive/negative) can also be used to develop more responsive services and ensure that success is replicated (Grela and Illerbrun 1998; Upshur 1991). Whilst research

suggests that children with ASD have made positive gains following VSSs training, their families are also recipients of intervention services and thus a target group for whom outcomes should be assessed (Bailey et al. 2006). Finally, there still appears to be disagreement amongst researchers in relation to the most appropriate model of partnership that should be employed by professionals (Cunningham and Davis 1985). Involving parents in developing strategies to achieve therapeutic goals raises questions and therefore this family-centred model needs to be explored further. Using a qualitative methodological approach, discussed in the next chapter, the study therefore aims to address the gaps in literature into parents working with professionals in relation to VSSs.

3. METHODOLOGY

3.1. Overview

“If the philosophical, strategic and instrumental strands of a research methodology are necessarily connected, it is because they should all reflect the most important element of research design, namely the research questions” (Blaikie 2010, p. 17). The research purposes were:

1. To establish if parents participating in the study (who decided together with professionals that support around VSSs would be provided) experienced the support to be of value/benefit and to highlight any problems with the support to aid the development of future service provision.
2. To examine the effectiveness of the support provided by exploring and eliciting the views of parents of pre-school children with autism, about changes they perceived in their child’s behaviour and communication skills as a result of the support.
3. To examine the effectiveness of the support by exploring and eliciting the views of parents of pre-school children with autism, about changes they perceived in their own understanding of what VSSs are and how they are used. Also, to determine whether parents noticed changes in their own abilities to use VSSs following support.
4. To examine the model of collective empowerment, when planning goals and service provision around VSSs, through critical reflection.

This chapter therefore discusses the methodological framework, and expounds the research strategies and instruments utilized within the study in order to investigate the research questions. It outlines the advantages, disadvantages and reasons for the selection of: an interpretivist approach, a qualitative design, and a case study methodology in the context of the research questions. The rationale for selecting two data collection tools are explained, and the implementation of the research is described. Ethical

issues, as well as data analysis procedures, are also outlined.

3.2. Selecting a research paradigm/philosophy

A research paradigm can be understood as “a lens through which we view the world” (Collins 2010, p. 38). It is described as the viewpoints adopted by the researcher to guide him/her through the progression of the research (Denzin and Lincoln 2005). A range of research paradigms therefore exists. The two, prominent paradigms considered for this research were: *Positivism* and *Interpretivism* and these are examined in turn below. Before addressing these research paradigms, it is important to note that research paradigms in the area of autism are debatable (Glynne-Owen 2010), possibly because of discussions over what research in the area of autism should look like. Most of the research in the field of autism is for the most part concerned within a merely positivist paradigm (Glynne-Owen 2010). It is therefore the researcher’s aim to explore this paradigm and argue the case for moving forward into a more qualitative, interpretivist approach in the field of autism.

According to Denzin and Lincoln (2005), a research paradigm constitutes three elements: ontology, epistemology and methodology. Blaikie (2000, p. 92) refers to ‘ontology’ as “concerned with the nature of social reality”. Therefore, what is reality? The epistemology of a paradigm refers to “what kinds of knowledge are possible – how we can know these things” (Blaikie 2000, p. 92). How can we know reality? It is defined as the link between the researcher and the reality (Carson et al. 2001). Lastly, the methodology is concerned with the procedures employed to obtain knowledge of social reality (Blaikie 2000). How do you go about finding out?

3.2.1. The positivist paradigm

The positivist paradigm refers to the scientific method, where the goal is to assess a theory or explain an occurrence through observation and measurement (O’Leary 2004). The ontology of the positivist paradigm assumes that there is a single truth or reality (Schunk 2008). The

epistemological side of this paradigm is therefore that reality can be measured and observed in an objective way (Schunk 2008) according to Wilson (2010, p. 10):

if you assume a *positivist approach* to your study, then it is your belief that you are independent of your research and your research can be truly objective. Independent means that you maintain minimal interaction with your research participants when carrying out your research.

A positivistic paradigm tends to favour quantitative research, and statistical methods for data analysis (Travers 2001).

Research within the field of autism and VSSs is often seen in favour of using objective, quantitative measurements (e.g. Bryan and Gast 2000; Green et al. 2004; Starr et al. 2006). Quantitative approaches are commonly concerned with a collection of items that are gathered together to form a total quantity (Robson 2002). The role of the researcher is therefore to observe, collect data and interpret it through an objective approach resulting in quantifiable research findings (Dudovskiy 2016; Levin 1988). Although widely used, quantitative approaches are generally appropriate in situations where one is “trying to establish cause-effect relationships between or among variables” (Williams et al. 2007, p.100) and generalisation of findings (Chisnall 2001). However, the quantitative approach and the positivist paradigm have been criticized for disregarding significant qualities of human lives (McCracken 1988). The positivist paradigm therefore assumes that the researcher is autonomous and interested in collecting factual data (Dudovskiy 2016). Most of the research concerning the impact of early childhood intervention methods on children with ASD tends to support a positivist paradigm, “identifying and analysing the deficits of the condition, and designing and testing techniques that develop ‘normal functioning’ in children with an autism diagnosis” (Glynne-Owen 2010, p. 2). Such studies

tend to make use of standardized assessment tools. In reality, these tools require: a human understanding of what is being observed, how the participant reacts to the environment, to the researcher, and to the assessment being presented (Glynne-Owen 2010). By using a purely quantitative approach, the opinions of those being researched are not examined.

Two extensively researched intervention methods which have undergone thorough, experimental examination are *TEACCH* and *ABA* (Mesibov and Shea 2009; Lovaas 1987; McEachin et al. 1993). These therapy programmes were described briefly in the literature review, Chapter 2. Additionally, the impact of VSSs cultivates the same positivist paradigm (e.g. Ben Chaabane et al. 2009; Kashinath et al. 2006; Krantz et al. 1993). One study carried out by Massey and Wheeler (2000) attempted to determine the effectiveness of a visual schedule with a 4-year old diagnosed with autism. The child was prompted to use the schedule until prompts were faded. "A multiple baseline across activities (work and leisure) assessed performance across baseline, treatment, and maintenance conditions with stimulus generalization being assessed during a third activity (lunch)" (Massey and Wheeler 2000, p. 326). They concluded that children with autism can gain the essential skills to use activity visual schedules independently and also generalise these skills to other situations. However, with a sample of one child, it can be criticized that their results cannot be made generalizable to the wider population of children with autism, who often present with differing characteristics (Glynne-Owen 2010). Additionally, parent perceptions of intervention programmes are often measured quantifiably. For example, Sellars et al. (2002) used pre- and post-test assessments to determine parents' stress levels following autism-specific intervention carried out with their children. The issue with such studies is that they fail to explore the uniqueness of children with autism and their parents. Therefore, how such studies can be beneficial to parents, children with autism, and professionals working with a diverse range of personalities is debatable. For this reason, another paradigmatic

understanding is needed. As this research integrates human interest, an interpretivist paradigm was thus considered.

3.2.2. The interpretivist paradigm

Interpretivism is “associated with the philosophical position of idealism, and is used to group together diverse approaches, including social constructivism, phenomenology and hermeneutics; approaches that reject the objectivist view that meaning resides within the world independently of consciousness” (Collins 2010, p. 38). The position of interpretivism in relation to ontology and epistemology is that interpretivists believe that there is no single reality and that this is created by individuals (Hudson and Ozanne 1988).

Interpretivism involves the researcher interpreting features of the study; therefore the knowledge obtained is socially constructed as opposed to objectively determined (Carson et al. 2001; Mertens 2005). It considers the researcher as a social person who welcomes the dissimilarities amongst people (Saunders et al. 2012). The researcher, the research participants and knowledge cannot be disconnected since the researcher is the informant of the reality (Hudson and Ozanne 1988; Mackenzie and Knipe 2006). The researcher therefore depends on the participants’ perspectives of what is being studied (Creswell 2003). Additionally, interpretivist research generally concerns understanding meanings/subjective experiences (Neuman 2000), usually evolving at the end of data collection, and can utilize a variety of methods to understand diverse features of what is being studied (Dudovskiy 2016). Whilst a mixture of both qualitative and quantitative data collection methods can be used under this paradigm, interpretivism commonly uses qualitative data collection methodology (Mackenzie and Knipe 2006). The methodology employed is discussed in section 3.4.

There appears to be a primarily positivist response to data collection and analysis in the area of autism. The views of parents of children with autism, particularly in relation to VSSs, have been neglected. The decision to

consider parents' responses with a more interpretivist response to data collection and analysis was therefore chosen as a way of creating an innovative piece of research. Furthermore, there exists a presumption that researchers and professionals know exactly the benefits and challenges of using VSSs, and often speak for children with autism and their parents. For example books such as that by Cohen and Gerhardt (2015), providing recommendations to parents on how to develop VSSs, are widely available. Many recommendations are made based on knowledge that some children with autism process visual information more easily when compared to other methods of communication (Quill 1995). Additionally, most of the research available includes a limited number of children, for example two boys in Dettmer et al.'s (2000, p. 168) quantitative study on the use of VSSs to facilitate transitions, with sweeping conclusions, "visual supports are easy to implement in many environments". Studies such as these disregard the opinions of parents. It has therefore been recommended to use an interpretivist response to analyse real life, valuable experiences of parents of children with autism (Glynne-Owen 2010). Indeed, according to McConachie and Diggle's (2007, p. 120) systematic review on parent implemented early intervention, "very few studies had adequate research design from which to draw conclusions about the effectiveness of parent-implemented early intervention".

3.3. Qualitative and quantitative approaches

A significant consideration in the choice of data collection methods for this research was the aim of investigating and evaluating parental perspectives of VSSs, as this was lacking in literature. In pursuance of this aim, both qualitative and quantitative research approaches were considered. The drawbacks and advantages of qualitative and quantitative research have been thoroughly debated throughout the years. A qualitative approach allows the researcher to explore ideas in their natural settings (Denzin and Lincoln 2005). It is subjective and not focused on generalisation (Patton 1990). This also ties in with the goal of interpretivist research, which aims to understand

new perspectives (Chisnall 2001) as opposed to generalizing findings (Hudson and Ozanne 1988). Berger (2014, p. 8) defines qualitative research as:

generally conducted in natural settings and uses data that are words or text rather than numeric to describe the experiences being studied. Qualitative studies are guided by research questions and data are collected from a small number of subjects, allowing an in-depth study of a phenomenon.

According to Denzin and Lincoln (2005), research sits within one of the two methods described above. The positions taken by researchers vary. Some see the two approaches as separate (Hughes 1997), whereas others feel they can be combined and are therefore not separate (Pring 2004). A research type, such as those discussed in section 3.4, can therefore use both quantitative and/or qualitative research methods (Merriam and Tisdell 2016). Mixed methods research, which involves combining both approaches, has been described as a more reliable approach, which provides a greater explanation of what is being investigated (Ary et al. 2010). From experience, working as a Speech and Language Therapist with families of children with autism, it is also not unusual to combine more than one treatment method. In selecting a data collection method, the same position was experienced. Whilst it seemed logical to mix both methods, there are also disadvantages and these should be acknowledged (Barbour and Barbour 2003). Firstly, whilst it appears to be a recent trend in research, mixed approaches require the researcher to have a varied set of skills, as well as additional time and resources to guarantee a successful design (Forthofer 2003). As a researcher with limited quantitative research experience, this presented as a challenge. Indeed, mixed approaches are generally carried out by teams of researchers with complementary skills as opposed to single researchers (Gerrish and Lacey 2010). Additionally, it was felt that in order to maintain the quality of the research, using one approach as opposed to two would produce a higher standard of research. The idea of using mixed

methodologies was therefore abandoned. Bryman (2001) argues that selecting between a qualitative or quantitative approach is dependent on the research question(s) being asked. Also, “researchers sometimes use one or the other, depending on their own epistemological stance” (Holloway and Wheeler 2010, p. 15). In order to answer the research questions and to fill the gap in literature, a qualitative approach was adopted to examine the different interpretations of the participants, incorporating what the parents in the service saw as more or less important (Walliman 2005).

3.4. Qualitative methodology

Qualitative approaches have been used by researchers to investigate perceptions and opinions of participants (Robson 2002). The foundation of qualitative research “lies in the interpretive approach to social reality and in the description of the lived experience of human beings” (Holloway and Wheeler 2010, p. 3). Qualitative approaches are not only designed around paradigm, but also the study design (Hyett et al. 2014). Following a literature search of published studies, with researchers defining ‘methodology’ and ‘methods’ differently, it became clear that there are diverse types of qualitative research approaches and therefore selecting one to best fit this study presented as a challenge. In terms of methodology, popular types include: *grounded theory*, *ethnography*, *phenomenological research*, and *case studies*. These are discussed briefly in turn below:

Grounded theory focuses on creating a theory and examining social relationships (Crooks 2001). Grounded theory was eliminated from the start as it was not the aim of the research to generate new theory from data (Glaser and Strauss 1968), but rather to understand an intricate situation. Ethnographic studies tend to concentrate on culture and customs (Leininger 1985). Ethnography was also rejected as this typically involves the researcher immersing themselves in the everyday life of the people being studied (Grix 2001), which was not possible due to the ethical constraints of the research. Conversely, phenomenological studies examine the lived

experiences of people through the descriptions provided by the participants (Speziale and Carpenter 2007). This research process involves what is known as 'bracketing' where the researcher puts aside their own feelings and experiences (Tufford and Newman 2010). Gerrish and Lacey (2010, p. 8) argue that this is not possible to achieve, "researchers are not divorced from the phenomenon under study. This means reflexivity on their part; they must take into account their own position in the setting and situation, as the researcher is the main research tool". Phenomenology did not appear to fit with the research questions proposed, specifically the evaluation of the model of collective empowerment through critical reflection and previous experience. In light of these approaches and the need to find a more flexible approach, case study research was considered.

3.4.1. Qualitative case study methodology

As this research requires collecting data to understand an intricate situation (Yin 2009) and examine an actual clinical situation in detail (Jacelon and O'Dell 2005), a qualitative case study approach was considered. Notwithstanding continuing debate about reliability, and recounted barriers in contrast to other approaches, case study is a progressively accepted approach among qualitative researchers from various disciplines (Thomas 2011). Denzin and Lincoln (2011) distinguish it as an individual qualitative research approach. Case studies consider the case being studied as well as the research questions (Hyett et al. 2014). Case study research is therefore considered appropriate when research questions seek to evaluate the support provided within a particular setting (Albright et al. 1998). The purpose of this case study, exclusively qualitative in design, is to understand how parents feel about the support provided, how they feel about their child's skills following the support, and how they feel about their own abilities to understand and use VSSs following support.

Qualitative case study research, as described by Merriam and Tisdell (2016, p. 37), "is an in-depth description and analysis of a bounded system". Case

study research has been approached from different viewpoints. For example, Stake (1995) approaches it from a social constructivist viewpoint, where as Yin (2012), approaches it from a post-positivist one. Considering Stake's (2005) view on case studies, in order to tie into the interpretivist position discussed by the researcher, the defining characteristic of case study research is the unit of study – 'the case'. This concurs with Merriam and Tisdell's (2016) view on what case studies are. Merriam and Tisdell (2016, p. 38) define 'bounded system' (the case) as a "single entity, a unit around which there are boundaries . . . The case, then, could be . . . a program, a group, an institution". Related to the focus of this research therefore is the model of parent-professional partnership employed for providing support around VSSs, in a particular autism-specific early intervention service within a city health board area of the Republic of Ireland. What is common is that the parent-partnership model used within this service (as presented in Chapter 2) can also be seen in other disability services in Ireland. The service in question was the first autism service to be set up within a specific county in Ireland. An interpretive approach to qualitative case study research "supports a transactional method of inquiry, where the researcher has a personal interaction with the case" (Hyett et al. 2014, p. 2). In this study therefore, a Speech and Language Therapist (the researcher) working in the service collecting data directly from service users.

Researchers such as Luck et al. (2006), Meyer (2001), Thomas (2010) and Tight (2010), have considered qualitative case study research as being inferior and poorly founded when compared to other approaches. Giddens (1984) argues that data cannot be generalised beyond the case itself. Conversely, Yin (2009) believes the aim of case study research is to link findings from a particular case to a theory, therefore an analytic generalisation, as opposed to generalising findings in a statistical sense. The aim of this research is to produce a detailed description of a situation and not to change a case into a type of macroscopic study (Hamel et al. 1993). Case studies offer an explanation as to why things are happening in a particular

setting and an understanding of the diverse interactions within that setting, as opposed to declaring that they do occur (Walsh and Wiggins 2003). Additionally, Creswell (2013) discusses how within case study research; data collection should be in-depth, encompassing various data collection tools to present a description of the case and later case-based themes.

3.5. Data collection tools

This is a qualitative study guided by the principles of case study research. To collect data, it was felt that using a method that honours the family support philosophy being studied would be best suited. Mackenzie and Knipe (2006) present: interviews, observation and document reviews as examples of data collection tools. Firstly, observational techniques were considered as a method for collecting firsthand data on the process being studied, as observations collect in depth information (Robson 2002). Interviews also allow for a comprehensive understanding of peoples' views (Monette et al. 2011). However, one disadvantage of both interviews and observational techniques is that participants may behave differently knowing that they are being watched (Landsberger 1958). In order to reduce researcher bias, none of the families selected worked directly with the researcher as a clinician. Time, costs and small sample size are also another limitation of using observational techniques (Yin 2009). It was felt that observing participants would not provide the researcher with an opportunity to answer the research questions proposed in full. Therefore, face-to-face interviewing was considered. Interviews have been used to examine people's "contextual experiences and the meaning they hold" (Holloway and Jefferson 2000). They are useful when trying to access people's stories and opinions (Silverman 2005). The interview as a data collection tool is affiliated to the interpretivist paradigm (Kvale 1996) and thus was considered suitable for this study.

3.5.1 Interviews: focus group and individual interviews

There were two parts in the present study:

- Part 1: A Focus group
- Part 2: Semi-structured individual interviews

Interviews were selected as they offer comprehensive information and can be individual or group (Rice and Ezzy 2000). Merton et al. (1990) have suggested conducting both focus groups and individual interviews as a way of allowing evaluation of the two methods. It has been suggested that using multiple methods of data collection can lead to a more substantial and accurate research study (Yin 2009). Whilst it was felt that the term “accurate” appears to indicate that the purpose of combining data collection methods is to claim validity, multiple data collection methods can also be used to reveal differences in opinions of the same phenomenon being studied (Moran-Ellis et al. 2006). Indeed, it is acknowledged that individual interviews may produce different results from the group interviews, bringing up issues of validity (Kitzinger 1994). Validity is rooted in the positivist perspective as opposed to the interpretivist paradigm selected for this research study and therefore this idea was rejected.

Detailed individual interviews allow access to the experiences, inner perceptions and feelings of the different participants and, through interaction with the researcher, reflect on their responses (Fontana and Frey 2003). Focus group interviews additionally allow an understanding of the issues that are important to the group and the interactions among group members (Hansen 2006). Reflection on collective views can lead to new understanding of the issues discussed (Millward 2012). Conversely, Fern (1982) examined the results of individual and focus groups and found that group interviews did not generate additional or superior ideas when compared to individual interviews. Therefore, it is acknowledged that selecting both interview methods might not necessarily lead to new research. However, carrying out focus groups first can provide a useful basis for individual interviews carried out later on (Morgan 1997). Following this idea, a focus group and individual

interviews were selected as data collection methods. These are discussed in turn below.

The role of the researcher in the qualitative research process cannot be ignored. “Because the researcher is the instrument in semistructured or unstructured qualitative interviews, unique researcher characteristics have the potential to influence the collection of empirical materials” (Pezalla et al. 2012). Interviewer reflexivity and reflection on the way the participants engaged with the researcher during the interview process are considered and discussed in Chapter 5.

Part 1: A focus group

A focus group can be defined as “a group of interacting individuals having some common interest or characteristics, brought together by a moderator, who uses the group and its interaction as a way to gain information about a specific or focused issue” (Marczak and Sewell 2015, p. 1). The aim of carrying out a focus group was to obtain a general understanding of what families viewed as important. Focus groups are considered useful when multiple views or responses are needed on a specific issue (Letts et al. 2007). However, fewer questions can be asked in focus groups due to the various people responding to one question (Lysack et al. 2006). Although by reducing the number of questions a variety of responses to each question should emerge (Robson 2002), in order to support the findings of the focus group, additional information was gathered by conducting individual interviews. Another challenge however, is that some participants may remain passive listeners and choose not to become involved in the discussion (Krueger and Casey 2009). Others may take over the group conversation (Brannen and Halcomb 2009). Therefore, it is important that strategies were used, such as appropriate questioning or commenting, to try to involve the whole group (Millward 2012). Questions such as: “How have you and your child changed since receiving support around VSSs?” were asked. Such questions should have allowed participants to give a rich description of their

experiences and promote discussion (Britten 1995). The focus group consisted of 4 participants. These numbers were considered appropriate for a focus group that aims to obtain an in-depth understanding of parents' perspectives (Krueger and Casey 2009). More participants may have meant that not all members would get to participate (Eliot and Associates 2005).

Part 2: Semi-structured individual interviews

Semi-structured individual interviews were also used for gathering data:

Semi-structured interviews are conducted with a fairly open framework which allows focused, conversational, two-way communication. The interviewer follows a guideline but is able to follow topical trajectories in the conversation that may stray from the guide when it seems appropriate. Not all questions are designed and phrased ahead of time. The majority of the questions are created during the interview, allowing both the interviewer and the person being interviewed the flexibility to go into details when needed. (Keller and Conradin 2018, p. 1).

These were used to supplement the information gained through the use of the focus group and also investigate in more detail themes that surfaced from the focus group (O'Leary and Miller 2003). It was also felt that a more personal and intimate insight would be gained through detailed interviewing (Denzin and Lincoln 2003) because they allow participants to explain ambiguity (Pontin 2000) and talk freely about what is important to them (Cozby 1993). Unlike 'unstructured' interviews, semi-structured interviews are designed to give "a sense of order from which to draw questions from unplanned encounters" (David and Sutton 2004, p. 87) and therefore these were selected. The aim of the research is to gather representative data; therefore 6 participants would be sufficient (Swetnam 2000).

3.6. Setting

The study took place during March and May 2014 in an autism-specific early

intervention service within a city health board area of the Republic of Ireland. The aim of this service is to provide a comprehensive and family-centered service to children with ASD and their families. The participants were chosen from this service as it was one of the few that was committed to working in partnership with parents of children with ASD. Moreover, issues of access and convenience contributed towards this decision. Services are divided into early intervention services and services for older children. Early intervention staff provide services to approximately 500 children.

3.7. Selection of participants

Purposive and criterion based sampling was chosen as a sampling strategy to allow the research to seek richness of data on the phenomenon being studied (Ezzy 2002). This method involves purposeful selection of participants that meet some criterion to provide significant information that cannot be obtained from other alternatives (Guba and Lincoln 1985). As opposed to quantitative measures, qualitative approaches use fewer participants chosen for their potential to supply representative data (Creswell 2002). The stipulated criteria are contained in Table 1:

The stipulated criteria are parents (mothers or fathers) of young children who:

1. have a diagnosis of ASD or SCD as defined by the *Diagnostic and Statistical Manual of Mental Disorders - 4th or 5th Edition* (American Psychiatric Association 1994; American Psychiatric Association 2013);
2. had identified together with the trans-disciplinary team that they would like to work on a visual support therapy tool for their child;
3. had received support around VSSs based on their priorities;
4. had attended the early intervention service for at least 6 months and no more than 12 months.

Table 1. Criteria for selecting participants.

In the autism service selected, not all parents and professionals working together would have identified VSSs as a goal to be worked on. Therefore, those families who had not identified VSSs support were not considered for this study. As this evaluation concerns experiences of parents who have attended the service and received VSSs support, data was collected from parents who had received support for 6-12 months. Families of children attending the service are generally attached to the service for at least 6 months. Goals are reviewed annually with families. Data was gathered from families still attending the service or who left not more than 3 months ago. This ensured that data was collected soon after support was received.

The sample was comprised of a total of 10 participants. Of the initial 500 children identified from file reviews, 91 children met the inclusion criteria. Their parent(s) were invited to participate in the study. 17 expressed interest in participating in the research. 10 were then selected (6 for the individual interviews and 4 for the group interview). A sample of 10 was considered sensible and suitable, given the limitations of this study. Additionally, the aim of the study was to obtain in-depth and detailed information about participant experiences of VSSs, as opposed to risk obtaining a less in-depth analysis often linked with larger sample sizes (Boyatzis 1998). Participant selection is discussed in more detail in Section 3.10.2. Sample size is further explored in Chapter 5.

3.8. Ethical considerations

In March 2013, ethical approval was sought from the relevant health service ethics committee in Ireland with consent achieved following minor alterations (Appendix 3). However, during the course of the research, significant alterations to the proposed research were made and therefore approval was again sought from this committee in January 2014. Changes to the data collection methods and aims of the research meant a further application was required. Consent was again achieved following very minor amendments to the study's focus group debriefing procedure (Appendix 4). An application

was later made to the *Queen Margaret University* research panel with full ethical approval granted (Appendix 5). The main ethical issues, as described by Cohen et al. (2000), included: informed consent, confidentiality and anonymity, storage and handling of data. These are discussed in the next section.

3.8.1. *Informed consent*

Written consent was obtained by participants signing a consent form at the start of the focus group and interviews (Appendix 6). Participants were informed that participation was voluntary and that they were under no obligation to take part. They were informed that they may skip questions and/or withdraw from the study at any time during data collection without any negative consequences.

3.8.2. *Confidentiality and anonymity*

It was made clear that responses would be kept confidential to the researcher. During the interviews, participants were asked not to identify members of staff. They were told that interviews would be audiotaped and later transcribed in written format. Transcripts would not contain any identifying information. The identity of the service would remain unidentified. Names and personal details would be masked to protect identities. Contact details of the researcher were provided should participants have wished to discuss anything further.

3.8.3. *Storing and handling data*

Participants were informed of the retention period of data, and how it would be stored before being destroyed. Access to data was carefully guarded and used only for the purposes of this study. Participants were made aware of the different sets of data kept i.e. written and oral formats. Audio data was collected on an encrypted dictaphone and immediately destroyed following transcription. Access to computers and manual files was restricted to the researcher. Printouts and waste papers were shredded and discarded

carefully. Participants were informed that access to recordings and transcripts would be guarded. Data was entered into an encrypted laptop. Participants were given the opportunity to check interview transcripts and revise/retract any statements they made before the researcher began analysing the data (Appendix 7). Participants were informed that although the research findings would be shared with the health service in question, no identifying details would be cited.

3.8.4. *Consequences of involvement*

Although it was probable that participants would have the competence to give consent, it was possible that parents who participated in the interviews were left feeling that the information disclosed was more than intended. Although the information to be collected was personal, it was not unduly sensitive. Before giving consent to participate, participants were made aware that confidentiality would only be breached if during the interviews, information given indicated there was serious risk for the child or other person(s). Overall, consequences of involvement are hard to measure, however participants were asked whether they were satisfied with the discussion and asked to review transcripts. After the interviews, a debriefing took place. Participants were given a sheet with contact details of the researcher, a support service and their intervention team (Appendix 8). None of the participants experienced feelings or concerns that needed follow-up.

3.9. Pilot interviews

Prior to the group and individual interviews being carried out, a draft discussion schedule for both the focus group and individual interviews, was developed after consulting relevant interview literature (e.g. Eliot and Associates 2005; King and Horrocks 2010; Krueger 2002; Millward 2012; Morgan 1993; Rubin and Rubin 2012). Questions used to guide the interviews were also based on the aim of the research and previous discussion with other professionals working in the area of autism. This allowed for practice sessions to be set up (Dawson et al. 1993), to identify

issues such as using recording equipment, and also to assess the feasibility of the study (Van Teijlingen and Hundley 2002). The questions were first tested with a small group of professionals, who knew the study and the client group, to check if the questions were clear and if they would produce the required information (Krueger 1988). This pre-test consisted of colleagues, who were selected due to their experience in research, and Speech and Language therapists working in the area of autism with the population under investigation. At this point it was clear that the interview schedules were rather lengthy and therefore certain duplications of questions were deleted from the interview schedule. It was also recommended that some questions be reworded to make them more parent-friendly, less lengthy, and unambiguous. The order of the questions was also changed. Amendments were then made in light of the above suggestions and a second draft was devised.

The second draft was then piloted. Four parents who had received support around VSSs, and were attending a similar service in a different area, were invited. They were contacted by phone and their details obtained via file reviews. An effective interviewer should demonstrate qualities such as good listening and probing techniques (Eliot and Associates 2005). An experienced focus group facilitator was also invited to the pilot test. Comments regarding the researcher's interview skills, the interview questions and the room arrangement were sought (Robson 2002). As a result of the feedback from the initial pre-testing, little changes were required following the pilot test. Parents felt the questions were easy to understand. One question was split into two questions and another omitted and reworded following analysis of the parents' responses. Together with the focus group facilitator, it was felt that the probing worked well. The arrangement of the room and the researcher's interviewing skills appeared to make the parents feel at ease. More probing was needed at times to ensure that all parents had an opportunity to answer the questions. After implementing the suggestions, the draft schedule was then finalised. It was not felt necessary to pilot the

individual interviews as the draft questions were very similar. During both the group and individual interviews, wording and order of questions were changed depending on how the interviews progressed (Corbetta 2003). This format allowed for further clarification and explanation when new opinions emerged (Gray 2009). Open-ended questions were used to allow participants to give a rich description of their experience (Britten 1995). A finalised schedule of questions, for both the individual interviews and group interview, can be found in Appendix 9 and 10.

3.10. Procedure for the focus group and semi-structured individual interviews

Initially a list of names and addresses of the children and families attending the service were accessed using the service's computer database. Length of service provided was also identified through this database. Those participants who had a diagnosis of ASD or SCD, and attended the service for at least 6 months and no more than 12 months, were considered for participation in the study. Individual files were then reviewed to obtain documentation of individual goals around VSSs support. Families who had never worked directly with the researcher were considered for participation in the study. Not knowing the participants ensured bias was kept to a minimum. In total, 91 participants met the inclusion criteria.

3.10.1. Invitation letter

The identified participants received an invitation to participate in the research (Appendix 11). The letter introduced the researcher and invited parents to participate in a focus group or interview. Participants were informed about confidentiality issues and consequences of involvement in the study. The letter also included information about: the purpose and nature of the research, the focus group and interview procedure, and storage and handling of information being collected. Participants were informed about audio-recordings and data transcriptions. Participants were asked to fill in an expression of interest form (Appendix 11) if they wished to be involved in the

study. They were asked to select whether they wanted to participate in the group interview, individual interview, or either interview. This allowed for an improved recruitment rate.

After sending the initial letter, a reminder and thank you letter was sent, thanking participants for filling in the expression of interest form or reminding them to complete the form if they still wished to participate (Appendix 12). Participants who expressed interest in participating were assigned to the focus group or interview group based on their preferences. Out of the 17 who expressed interest, 5 identified that they wanted to participate in an *individual interview*, 3 selected the *group interview* and 9 selected *either interview*.

3.10.2. Selecting participants

The 5 participants who selected *individual interview only* were assigned to the individual interview part of the study. This meant that 1 more participant was required to make up the '6' participants required for the individual interview. Therefore, 1 participant, from the 9, who chose *either interview* was then selected using a 'lottery-type' selection and assigned to the *individual interview* group. The 9 names who selected *either interview* were placed into a box and 1 participant drawn up. Therefore, 6 participants were selected in total. All the individual interview participants happened to be mothers.

The 3 participants who selected *group interview only* were assigned to the group interview part of the study. From the remaining 8 *either interview* names, another was drawn out to join the group interview part of the study. In total, 4 participants were assigned to the group interview process (3 were mothers and 1 was a father).

Both mothers and fathers were invited to participate in the study. Participants who were selected or not selected due to sampling methods received a letter explaining this (Appendix 13). Those selected were informed that the

researcher would contact them shortly via phone. Participants were approached using the contact details provided by them in the expression of interest form. Those participating in the individual interview were asked about a mutually convenient time and location to meet with them to conduct the interview. Those participating in the focus group were informed of the time and location of the interview.

3.10.3. Carrying out the interviews

The focus group was carried out first. This took place within one of the service's buildings. Notes were taken by the researcher to ensure a complete understanding of what participants were saying was gained and also "as a fail-safe in case of a taping problem" (Robson 2002, p. 278). Following the focus group, the individual interviews then took place in the participants' homes. Both the focus group and individual interviews lasted approximately 60 minutes each (carried out on separate days).

At the beginning of both types of interview meetings, the information contained in the introductory letter (Appendix 11) was reviewed with the participant(s). The participants were asked to sign a consent form (Appendix 6). If the participants were comfortable about the process, a digital encrypted voice recorder was switched on and the interview proceeded using the interview guide devised (Appendix 9 and 10). The interviews were facilitated by the researcher. After the interviews, a debriefing occurred to check how the participants were feeling and/or if they had any concerns or questions following the interview. A debriefing contact sheet was provided (Appendix 8). None of the participants identified any concerns that required follow-up. Participants were also informed that they could receive a summary of the project upon request, following completion of the project. The interviews were then transcribed verbatim. Participants were then provided with a copy of the interview transcripts (by post) to review the material they offered and revise/retract any statements they made. No changes were identified.

3.11. Data analysis

Data from the focus group and semi-structured interviews were analysed using thematic analysis (Burnard 1991). Thematic analysis is considered to be a flexible and accessible method for analysing qualitative data (McLeod 2011). It can “provide a rich and detailed, yet complex account of data” (Braun and Clarke 2006, p. 5). The rationale for its use is partly because it offers a systematic approach to analysis. Braun and Clarke’s (2006) guidelines to conduct data analysis are presented below:

Phase	Description of the process
1. Familiarising yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic ‘map’ of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Table 2. Phases of thematic analysis (Braun and Clarke 2006, p. 35).

In the next chapter, Chapter 4 ‘data analysis’, participants perceptions are reported and the ways they made meaning of their experiences are explored (Braun and Clarke 2006). Themes within the data have been identified. The

parent-professional model of service delivery has been used as the basis for interpreting parents' experience in this research. The development of themes involved interpretative work, and the data analysis is not only descriptive but also an examination of "the *underlying* ideas, assumptions, and conceptualisations - and ideologies - that are theorised as shaping or informing the semantic content of the data" (Braun and Clarke 2006, p. 13). This is discussed in more detail in the next chapter.

3.12. Summary

This chapter has explored an interpretivist paradigm, a qualitative design, and a case study approach. Data collection methods, and procedures for implementation of the research were also considered. Individual interviews and focus groups were examined as well as the selection of participants. Ethical considerations and data analysis procedures were also explored. The next chapter (Chapter 4) presents the research findings and proposes key themes, which are subsequently discussed in more detail in Chapter 5.

4.0. DATA ANALYSIS

4.1. Overview

This chapter presents the findings that emerged from the research analysis of the study. A qualitative thematic analysis methodology was used to examine parental perspectives of the support they received in relation to VSSs. In addition, this study examines the effectiveness of the support provided by eliciting the views of parents in relation to any changes in their children's skills as well as their own abilities to use VSSs following the support they received. Thematic analysis was used as it allowed a considerable amount of data from participants to be explored into a meaningful description (Boyatzis 1998). Braun and Clarke's (2006) guidelines on thematic analysis were used during data analysis, as these explain a clear and relatively recent account of the method. Using thematic analysis allowed the researcher to present the results in a distinct format (Silverman 2005). Additionally, thematic analysis is not restricted to one particular epistemological stance and provides a systematized method for identifying key themes (Braun and Clarke 2006; Boyatzis 1998). This chapter also presents a rationale for choosing thematic analysis. Interview data was collected by means of a focus group and a series of semi-structured, face-to-face interviews. As part of the data analysis process, illustrative quotes have been used to summarise the data obtained. Results revealed; the importance of working with professionals, the improved changes in the skills of parents and their children, and data on the experiences of parents using VSSs. Interpretation and discussion of the data obtained is presented in the next chapter, Chapter 5.

4.2. What is thematic analysis and why select it?

"The purpose of qualitative analysis is to interpret the data and the resulting themes, to facilitate understanding of the phenomenon being studied" (Sargeant 2012, p. 1). Thematic analysis focuses on identifying patterns to produce explanations of behaviours (Hammersley and Atkinson 1995).

Although thematic analysis is widely used in qualitative research (Braun and Clarke 2006), the actual process of how it should be carried out is not often clear (Boyatzis 1998; Roulston 2001; Suddaby 2006). It is however used across disciplines, and is generally thought to be positioned within the interpretivist paradigm (Benner 1994), which is the approach chosen for this study. The aim of thematic analysis is to produce a narrative account and summarise data into themes to explain the phenomena being studied, as opposed to developing a theory to describe results (Ryan and Bernard 2000). Whilst researchers, such as Ryan and Bernard (2000), do not consider it as a specific method for analysing data, Braun and Clarke (2006) argue that thematic analysis can be viewed as a method. "Through its theoretical freedom, thematic analysis provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of data" (Braun and Clarke 2006, p. 5).

Unlike grounded theory, thematic analysis is not bound to a particular epistemological position (Braun and Clarke 2006). It is not a theoretically informed model for research and analysis and allows the researcher to combine data from a variety of sources (Boyatzis 1998). Despite its flexibility, using such a flexible approach, without well-defined guidelines has been criticised (Antaki et al. 2002). Braun and Clarke (2006) therefore offer guidelines to explain how thematic analysis should be carried out, but also offer flexibility in how it is used. According to Braun and Clarke (2006), the analysis of the data consists of six phases. Data analysis begins by immersing oneself in the data, generating initial codes, searching for and reviewing themes, defining and naming themes and trying to explain the 'story' of each theme from all perspectives. This therefore offers the researcher a pleasing, clear and unsophisticated method for analyzing data, unlike more technical methods such as discourse analysis or conversational analysis (Javadi and Zarea 2016). However, notwithstanding these advantages, as with all data analysis methods, the difficulties in using this method need to be considered to avoid weak analysis. Hayes (2000) argues

that such difficulties are a result of poor analysis as opposed to thematic analysis itself.

Braun et al. (2015), argue that carrying out thematic analysis unprofessionally can result in serious damage, for example, the researcher reporting positive and desired outcomes. The aim of thematic analysis is to inform the reader what the data means or may mean, as opposed to simply providing a summary of organised data (Vaismaoradi et al. 2013). It is “considered the most appropriate for any study that seeks to discover using interpretations” (Alhojailan 2012, p. 10). It allows the researcher to understand issues in greater detail (Marks and Yardley 2004). However, it being a flexible method means that the researcher is required to be unambiguous about how data is analysed, in order to avoid pitfalls. For this reason, the step-by-step process is explained and presented in section 4.3., with use of appendices to further illustrate the process. As stated by Riecher and Taylor (2005, p. 549) “rigor lies in devising a systematic method whose assumptions are congruent with the way one conceptualizes the subject matter”. Additionally, Braun and Clarke (2006) suggest a checklist in order to ensure correct thematic analysis. This was considered and can be seen in Table 3 overleaf:

Table 2: A 15-Point Checklist of Criteria for Good Thematic Analysis

Process	No.	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.
Coding	2	Each data item has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
	4	All relevant extracts for all each theme have been collated.
	5	Themes have been checked against each other and back to the original data set.
	6	Themes are internally coherent, consistent, and distinctive.
Analysis	7	Data have been analysed - interpreted, made sense of - rather than just paraphrased or described.
	8	Analysis and data match each other - the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organised story about the data and topic.
	10	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.
	13	There is a good fit between what you claim you do, and what you show you have done - i.e., described method and reported analysis are consistent.
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15	The researcher is positioned as <i>active</i> in the research process; themes do not just 'emerge'.

Table 3. Checklist of criteria for good thematic analysis (Braun and Clarke 2006, p. 36).

4.3. Analysis of focus group and individual interviews

The primary objective for data collection was to represent the subjective viewpoint of parents, who shared their experiences and perceptions of working with professionals in relation to VSSs. The aim was to explore the ways participants made meaning of their experiences. The use of thematic analysis was therefore driven by the research questions and theoretical

assumptions of this research study. By using a focus group and individual interviews, data was generated to allow 'themes' to be identified thus illuminating the experience of the participants. A 'theme' is defined as "something important about the data in relation to the research question, and represents some level of *patterned* response or meaning within the data set" (Braun and Clarke 2006, p. 10). In terms of frequency, themes were not identified based on how often they occurred in the data collected. Braun and Clarke (2006), argue that researcher judgment can be used to determine what constitutes a theme. "The 'keyness' of a theme is not necessarily dependent on quantifiable measures – but in terms of whether it captures something important in relation to the overall research question" (Braun and Clarke 2006, p. 10). More specifically, as this research study is qualitative it was important to collect information that captures what parents felt was important, and not base it on how often it was mentioned. Prevalence was therefore counted at the level of each individual piece of data collected. It was not counted in terms of how often the theme was articulated. However, in order to demonstrate that themes did indeed exist within the data, and add to the rigour of the data analysis, 'conventions' such as "a number of participants" have been used. A detailed exploration of the emergence of three themes, based on the research questions, is presented throughout this chapter.

Whilst a priori themes were identified following the literature search, such as *parent-professional partnership*, the research questions could not be answered using a theoretical approach - due to limited research on the subject. It was essential to allow for the emergence of themes that had not been predetermined, particularly as this is a qualitative study. It was reasoned that data analysis would therefore be viewed as 'inductive' in order to develop themes (Braun and Clarke 2006). An inductive approach is open to participants' experiences, as opposed to looking for perceptions on issues informed by evidence-base. Another consideration, as recommended by Braun and Clarke (2006), was to determine the 'level' at which themes

needed to be identified. This analysis focused on the latent information and the interpretation of meaning, and was approached from an interpretivist epistemological perspective (as discussed in Chapter 3). Latent themes were explored as these allowed for a more interpretative account of the assumptions underpinning what parents said during the interviews. A latent approach “starts to identify or examine the underlying ideas, assumptions, and conceptualisations and ideologies that are theorised as shaping or informing the semantic content of the data” (Braun and Clarke 2006, p. 13). A latent approach is consistent with an interpretivist epistemological position “where broader assumptions . . . are theorised as underpinning what is actually articulated in the data” (Braun and Clarke 2006, p. 13). Given the experience of the researcher and the fact that she was actually working for the service under study, values and opinions of the researcher could not be excluded. Indeed, “researchers cannot free themselves of their theoretical and epistemological commitments, and data are not coded in an epistemological vacuum” (Braun and Clarke 2006, p. 12). From an interpretative perspective, meaning and experiences are socially constructed and replicated, as opposed to existing within individuals (Burr 1995).

4.4. Braun and Clarke’s (2006) phases of thematic analysis

Braun and Clarke’s (2006) phases of thematic analysis were followed, as per the reasons given above. Interviews were carried out in settings that were convenient for the participants, in the case of the individual interviews: their home, and in the case of the group interview: a work place setting.

4.4.1. Phase 1: Familiarising oneself with the data

Following collection of the data by the researcher, as discussed in Chapter 3, the data collected from the audio recordings was transcribed verbatim, reviewed and transcription errors corrected (Creswell 1998). The transcribed data was typed, stored and saved into a series of digital documents. Abbreviations were used to identify participants e.g. P1 (Parent 1), G (Group Participant). Once the documents were completed, these were printed and

initial ideas were jotted down manually in the margins of the transcribed interviews. The transcripts were read and re-read repeatedly. This process allowed for data 'immersion' (Braun and Clarke 2006). Transcribing the interview data from the audio recordings allowed the researcher to engage in a number of senses. Hand written analytic notes were made as the transcription process was being completed. Reading and re-reading the transcripts many times allowed for the researcher to become completely familiar with the data (Sargeant 2012). At this stage, the purpose was to begin to focus, "on patterns that emerge from the data itself" (Nishishiba et al. 2014, p. 286). Additionally, it was important that the researcher represented an accurate picture of what the participant said during the interviews. For this reason, verbal utterances, non-verbal utterances [e.g. laugh], and pauses (depicted as dots '. . .') were produced in the orthographic transcript. Pseudonyms were used to protect confidentiality. An example of part of a typed transcript can be seen in Appendix 14.

4.4.2. Phase 2: Generating initial codes

A coding task, which involved line-by-line coding, was then organised in order to systematically organise the qualitative data, facilitate interpretation of the results, as well as group the data and generate initial codes (Nishishiba et al. 2014). This step therefore involved production of codes. A 'code' refers to "the most basic segment, or element, of the raw data or information that can be accessed in a meaningful way regarding the phenomenon" (Boyatzis 1998, p. 63). The researcher therefore 'fixes' their data into meaningful groups (Tuckett 2005). See Appendix 15 for an example of codes applied to a sample of data.

Coding was first done manually as this allowed the researcher to further familiarize themselves with the data. This involved using colours to highlight text and identify patterns, underlining quotations, and writing notes in point form to link the transcription data to key ideas. All the data collected was given full and equal attention. Once this was done, it was then inputted into a

word document. This revision process ensured that the codes were further adjusted and refined. Revision also allowed for the development of a better understanding in identifying patterns (Nishishiba et al. 2014). A third process involved putting all the coded and collated data into one lengthy list. A sample of the code list from the participant transcripts is presented in Appendix 16 (Excerpt 1).

4.4.3. Phase 3: Searching for themes

Once the list of codes was identified and generated, the next phase involved organising the various codes into possible themes “and collating all the relevant coded data extracts within the identified themes” (Braun and Clarke 2006, p. 19). The identification of themes, as defined earlier, can be viewed as a ‘fresh’ level of coding to identify broader patterns in the data (Nishishiba et al. 2014). Braun and Clarke (2006), suggest using visual representations in order to aid this process. Words that summarised the grouping of codes were used as potential ‘themes’. A thematic map of this early stage can be seen in in Figure 9. This phase resulted in the identification of seven potential themes with some sub-themes. “A subtheme shares the same central organising concept as the theme it sits beneath, but develops a distinct aspect or element of it” (Braun et al. 2014, p. 120). Extracts of data coded concerning these potential, initial themes was also gathered (Excerpt 2: Appendix 16).

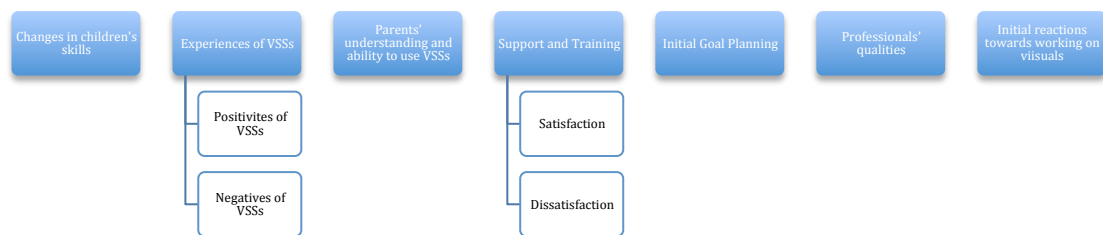


Figure 9. Initial thematic map showing seven main themes.

4.4.4. Phase 4 and 5: ‘Reviewing Themes’ and ‘Defining and Naming Themes’

The next two phases involved reviewing and refining initial themes. Once the initial set of themes and sub-themes were identified, they were reviewed with regard to maintaining, subdividing, or collapsing them as appropriate. All extracts for each theme were re-read and they were considered in terms of whether they formed a consistent pattern. A second thematic map was therefore created as can be seen in Figure 10 in the subsequent pages. During this phase it became apparent that some themes could be placed together as one theme. It was evident that, the theme “changes in children’s skills” needed to be broken down further into a variety of sub-themes and sub-sub themes as abundant and rich data concerning this topic was collected. Braun et al. (2014, p. 120) note that breaking down themes into smaller units is advantageous “when there are notable aspects of a theme that are worth highlighting”. The themes “initial goal planning”, “professionals’ qualities”, “parent support and training”, and “initial reactions towards working on visuals” (which concerned parents satisfaction/dissatisfaction with the way

they worked with professionals and service provision) were grouped under the theme “parent-professional partnership”. Parents’ “experiences of VSSs” was also sub-divided into what was concerned as being more relevant and accurate sub-themes. “Parents’ understanding and ability to use VSSs” was also sub-divided into sub-themes due to the presence of a considerable amount of data that needed to be refined. The theme was also re-worded to make it more concise and clear. Braun and Clarke (2006, p. 20) recommend that, “themes should cohere together meaningfully, while there should be clear and identifiable distinctions between themes”. Extracts of data coded concerning these themes were also gathered and organised during this process (Excerpt 3: Appendix 16).



Figure 10. Second thematic map showing four main themes (shown in red) and sub-themes (shown in blue).

The second thematic map, shown in Figure 10, was then refined and finalised to create a third, and final thematic map, as shown in Figure 11 overleaf:

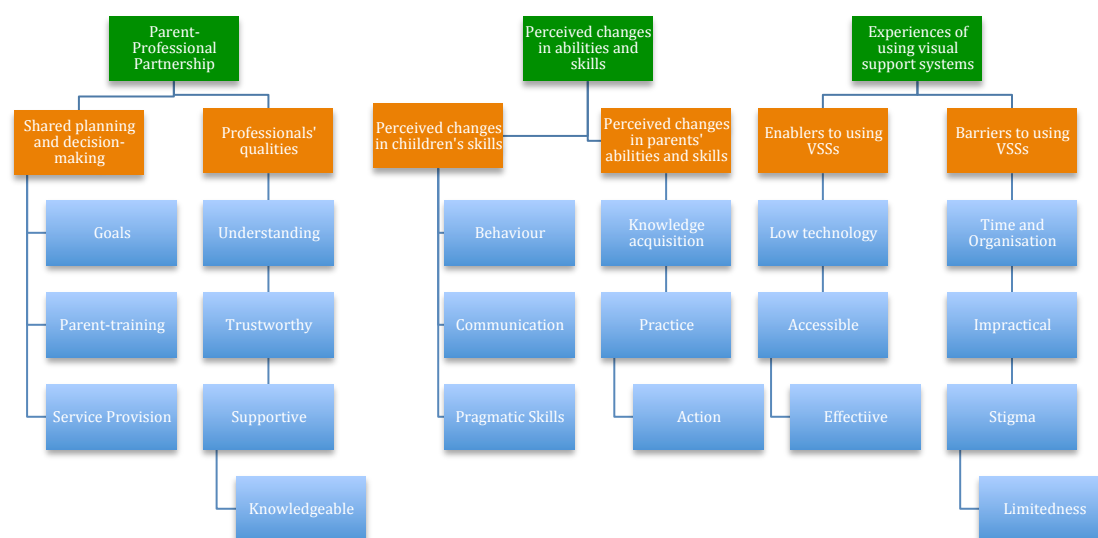


Figure 11. Final thematic map showing three main themes (shown in green) sub-themes (shown in orange) and sub-sub themes (shown in blue).

The researcher felt that coding had reached saturation point following the reviewing and refining of the coding. “As coding and generating themes could go on ad infinitum, it is important not to get over-enthusiastic with endless re-coding. It is impossible to provide clear guidelines on when to stop, but when your refinements are not adding anything substantial, stop!” (Braun and Clarke 2006, p. 21). Two to six central themes is what is generally recommended (Braun et al. 2014). Some sub-themes under the theme “parent-professional partnership” were grouped together to create two sub-themes as opposed to four. One overarching theme was used to encompass the two sub-themes related to changes in skills and abilities, therefore for both parents and their children. The theme concerning parents’ views on visuals as a therapy technique was also re-fined in order to make clear the crux of what the theme was about. Extracts of data coded concerning these themes were again revisited, organised and gathered to create a final list (Excerpt 4: Appendix 16). In order to ensure reliability of the coding process (Miles and Huberman 1994), and evaluate the identified themes, two

transcripts were randomly selected and coded by a fellow colleague for feedback. Miles and Huberman (1994) suggest that validating themes during data analysis is essential. No major conflicting results were reported during this process.

4.4.5. Phase 6: Producing the report

Following the described analysis, three major themes were ultimately extracted from the data. These were:

- Parent-professional partnership
- Perceived changes in abilities and skills
- Experiences of using VSSs

Each theme had two sub-themes and three to four sub-subthemes represented in the data. The themes, sub-themes and sub-subthemes are presented in Table 4 together with a definition for each theme to provide the reader with the principle of what each theme is about.

<i>Themes and Definitions</i>	<i>Sub-themes</i>
<p>1. Parent-professional partnership: The collaborative relationship between the parent of a child with autism and the professional involved.</p> <p>Professionals demonstrated a variety of characteristics parents believed were important to the partnership. Parents voiced their opinions around the planning and decision-making</p>	<ul style="list-style-type: none"> • Shared planning and decision-making (goals, parent training, service provision) • Professionals' qualities (understanding, trustworthy, supportive, knowledgeable)

process when deciding to work on VSSs.	
<p>2. Perceived changes in abilities and skills: Parents spoke about the process of learning a new skill. They spoke about the positive gains made by their children following the use of VSSs.</p>	<ul style="list-style-type: none"> • Perceived changes in children's skills (behaviour, communication, pragmatic skills) • Perceived changes in parents' abilities and skills (knowledge acquisition, practice, action)
<p>3. Experiences of using visual support systems: Parents spoke of the practicalities involved in using VSSs.</p>	<ul style="list-style-type: none"> • Enablers to using VSSs (low technology, accessible, effective) • Barriers to using VSSs (time and organisation, impractical, stigma, limitedness)

Table 4. Themes and sub-themes.

Compelling and illustrative quotes are presented in the next section to exemplify the themes, revealing the experiences of the participants in relation to VSSs. The aim is to “tell the complicated story of . . . in a way which convinces the reader of the merit and validity of . . . analysis” (Braun and Clarke 2006, p. 23). Each participant in the examples of quotations provided, to illustrate the themes, is identified by code (e.g. P1 (Parent 1) or G (Group)). For example, three dots denote a pause in speech. Fictitious names have been used to disguise the child's identity and/or any other identifying information - to protect anonymity as discussed in ‘ethical considerations’ (Chapter 3).

4.5. Theme 1: Parent-professional partnership

One of the themes that emerged from the data was that of ‘parent-professional partnership’. This related to the collaborative relationship between the parents and professionals who participated in the study.

Professionals demonstrated characteristics, which aided/hindered the relationship between the two. Parents voiced their opinions around shared planning and decision-making following the introduction of visual aids, and the support and training provided.

4.5.1. Shared planning and decision-making

During the interviews, most of the participants spoke about the relationship they had with the professionals whom they were working with e.g. the Speech and Language Therapist, the Teacher (see Figure 8, *Team Map*, p. 43). It was evident that it was the professionals who first introduced parents to the idea of using VSSs. Most had never heard about them prior to meeting a professional who worked in the area of autism:

P2: *and she said you should try PECS⁴ ...⁵ and we've never heard of it ... but sure we'd barely heard of autism at that stage*

P3: *his teacher ... would have told us all about PECS at that stage and introduced it ... and how it worked*

P1: *I wouldn't have known anything about just visual aids ... em ... she would have started with the first and next ... schedule ... I'd never seen anything like that before*

Some parents did describe how they had done some research themselves on visuals prior to getting their children's diagnosis:

P6: *I would have seen them online visual supports ... and when I started to ask the team they said yes ... so they were quite happy to share the information with me*

Professionals were required to introduce parents to VSSs, as these weren't necessarily common knowledge:

⁴ Picture Exchange Communication System (PECS) – as discussed in Chapter 2.

⁵ '...' refer to pauses in speech.

G: *when you are going about your daily life ... yeah there's visuals everywhere ... signs for speed ... and everything else ... but ... you just accept them ... you know ... you don't think that you're going to use that ... to dress your child*

Following the professionals' introduction of visuals to parents, participants demonstrated mixed reactions towards this idea. Some participants were more open to the idea once they obtained an understanding of the therapy tools or after they noticed "a huge improvement" (P4). Others were "happy to go with" (G⁶) the professionals' decisions from the start. The following quote illustrates one parent's thoughts following a professional's suggestion to use PECS:

P3: *when I did hear about it first ... I was actually really ... not ... not totally in favour of it ... I was very kind of ... I remember coming home and I was kind of like oh my god ... is this ... what you think my child is going to do ... like ... is my child just going to use pictures to communicate ... and I suppose that was kind of my first kind of ... negative reaction ... But I suppose it was more ... once we kind of ... you know ... got to know more about it and read more about it and that ... that you kind of understood well actually no ... this is kind of a method to help*

In terms of goals, not all participants felt that the decision to work on visuals was mutual. At times, it was the parent who did not support the idea of working on visuals:

P7: *any of the members of the team would feel very strongly despite the fact as a parent you might say yes ... but my child is verbal ... they seem to be ... one of the things they try to promote really does seem to be the visuals.*

Other times, it was the professionals who were "not so much in favour of" (P2) parents' decisions to work on visuals despite it being the child's "form of communication" (P2).

⁶ Group Participant.

Many found the training and support provided useful:

P1: *if I was trying to just start off on my own ... completely on my own ... I'd say it would be very daunting*

Information was mainly delivered via group training, demonstrations, home visits, discussions with professionals, and videos. Therapists displayed “schedules everywhere” (P1) within the clinic setting, giving the parent an opportunity to see how they were used. Group parent training was “very useful” (G) as it provided parents with an opportunity to obtain advice from someone who “knew what they’re talking about” (G). “Written information” (P2) was also valuable. As one parent described, having that written information ensured that if they encountered any difficulties when the professional was not present, they had something to refer to. Support was required to help parents understand the reasons behind using visuals and how they are used. Most of the information provided was specifically related to the children’s needs. Parents found the support helpful as it enabled them to clarify any questions they had and bounce off ideas:

P3: *when you’re kind of reading something in a book ... or you’re reading something in the Internet or whatever ... things are just so much more easy to understand when someone’s actually sort of sitting one-to-one and explaining stuff ... and showing you stuff*

Support from other parents as well as videos of other parents using VSSs were also helpful during group training:

G: *Yeah ... I found the ... advice coming from other parents about the ... use of visuals and its effectiveness ... is kind of more beneficial than some expert saying ... yes ... PECS have been proven in this study to ... you know*

Whilst the information was beneficial, some parents reported they would have liked more regular support; especially to make sure parents were “doing the right thing” (G):

P2: *reading the instructions on how to do something ... is miles away from having somebody who is proficient at doing it saying ... well read the instructions once ... have a go and then I'm going to come in and I'm going to hand over hand do it for you . . . I mean you can be swinging a golf club for years ... and reading and watching ... you know YouTubes or what have you ... until somebody comes and puts their hands around you and says move your grip slightly*

Regular support is required as it helps parents feel reassured that what they are doing is correct. Additionally, one parent described how parents are not professionals and therefore require the support from professionals. Understanding and using VSSs is a learning process. Furthermore, a lot of information is available on the Internet making it sometimes overwhelming for parents:

G: *you can be on the Internet sometimes and you're looking at stuff ... and you're thinking ... it's very academic.*

More support for the family is required, as opposed to just the child:

G: *Mum ... do you love Chris more than you love me? . . . And I said absolutely not fairy ... you know ... but that's how they feel because they think you're giving that time with the visuals ... they are things that people don't tell you... There has to be a support system around everybody else*

Few also reported a delay in services resulting in most of the research being done by them:

G: *the services weren't available for me . . . but if I had waited all of that time ... Chris wouldn't be where he is today*

4.5.2. Professionals' qualities

Professionals demonstrated certain characteristics that enhanced the parent-professional relationship. The majority of participants found the professionals to be: trustworthy, supportive, understanding, and knowledgeable. Some

described how professionals were “experienced” (P1) at using VSSs, and how parents “always got help” (P6) when parents asked for it. Nearly all parents appreciated it when the professionals created and prepared VSSs for them. However, professionals sometimes assumed parents knew what the professionals were talking about:

G: *Because when someone says do a social story ... you're thinking ... what? [Laughs] and then they'll say oh ... you can draw anything ... and then in the end ... when you actually see a few of them ... I found that quite useful and it's ah ... that's what they mean. And then ... yeah ... we use social stories all the time now.*

In terms of professionals' supportive qualities, some participants reported that they were not made to feel empowered to push schools to work on visuals. Some schools weren't as supportive of parents' decisions. At times, there appeared to be a lack of open communication between home and school.

P2: *I would have expected strong support and strong push ... that's fallen through. Because I had really hoped that if we had got that ... then they could have then pushed back on the school a little bit along with myself to say look ... you know*

However, some professionals did act as a link person between home and school/home and clinic:

P3: *I mean his teachers and stuff were very good ... but I suppose it was ... obviously it sort of all happened more in the school if you know what I mean. So sometimes it was hard to kind of ... you know ... bring everything home . . . I suppose the great thing about being with Olive Grove now is the fact that ... you know ... Clara has been great ... and ... you know in terms of I think she's been out three times ...*

Lastly, the information provided by professionals was sometimes delivered quickly. There was a lack of follow-up after the information was provided:

P4: *I was told about it ... and like ... it was explained to me quite quickly [laughs] ... and then I just had to get on with it.*

4.6. Theme 2: Perceived changes in abilities and skills

The second theme identified concerned parents' views on the process of learning a new skill. Parents also spoke of the changes seen in their children following the introduction of VSSs.

4.6.1. Changes in children's skills

Most participants reported significant improvements in their child's skills following the introduction of VSSs. The three main areas of development were: communication, behaviour, and pragmatic skills. The amount of change was not measured as this was beyond the scope of this study.

In terms of communication skills, parents noted an increase in their child's receptive and expressive language skills. Most parents reported an improvement in understanding of: commands and what is expected, events (and when they will happen), and changes in routines:

P1: *he knows there's a beginning ... middle and end to a particular event ... or a day*

G: *if he wants his time playing something ... and it's like ... not available ... the thing ... and he understands that*

G: *like he was five before he had a proper birthday party ... and that he actually knew it was his birthday ... we done that with social stories*

Parents reported that their children were more able to understand that a less preferred activity needed to be carried out before a preferred one:

P5: *if I'm trying to reason with him ... you know ... to have his dinner ... if he's watching the tele ... and he doesn't ... I'll say if you have your dinner and eat something I'll give you some sweets and I'll show him the biscuit visual you know*

Expressive language was also an area of improvement for most children with some parents reporting increased vocabulary and sentence length. Children were more able to express their wants, needs, choices, feelings, and initiate conversation following the introduction of VSSs:

P2: *she's starting to use some words again . . . she will make attempts to use the language.*

With regards to behaviour skills, the majority of participants reported that their children demonstrated less negative behaviours (e.g. whining, kicking), reduced “anxiety” (P5) and frustration. Children were more able to deal with change, manage their sensory sensitivities e.g. hearing different sounds in a supermarket (P5), and appeared calmer following the introduction of VSSs:

P6: *Massive changes. Massive ... we don't have ... we don't lie on the floor and bang our head off it ... anymore.*

Lastly, some parents reported improved social language skills:

P1: *verbally he's prob ... you know ... he's probably quite good if you assessed him ... but it's the whole social thing about starting conversations ... speaking appropriately ... using his words appropriately*

P6: *Loads more social ... yeah. Things like he'll come in ... I see you!*

4.6.2. Changes in parents' abilities and skills

Numerous participants spoke about the positive changes the support had on their understanding and ability to use VSSs. During the interviews it was noted that none of the participants mixed up any terminology and appeared to have a good understanding of words used to express different visual therapy tools, such as ‘visual schedules’ and ‘PECS’.

With regards to knowledge acquisition, most participants reported an improved understanding of the therapy tools following the support received. They felt it was a trial and error process and their knowledge increased over time (P1: "I learned and I grew with it"). Once they understood the therapy tools, they began to adapt the therapy tools based on their child's needs and their own preferences, thus "thinking of" (G) and creating innovative ways of using the tools. Visuals were removed, adapted and/or reduced based on their child's needs and development. Parents "consciously" (P6) decided where they wanted to place their pictures in the house once they started using them.

G: *He was toilet trained in school ... and he wasn't at home. And ... I was thinking like ... this isn't making any sense. And I stuck a picture ... we have a toilet downstairs and I stuck a picture of a toilet on the door outside ... and that was it. He started using the toilet. And I went well ... you know ... that's ... you know the kind of Eureka moment when you say ... right I'll continue on with the visuals.*

P3: *I was just kind of thinking ... ok ... right that's great ... he's letting us know that he wants the TV. But I was thinking realistically it must be incredibly frustrating when you turn on the TV ... it's like well what do you want? You know ... so I was kind of saying oh ... well hang on maybe if we do some ... some pictures ... and literally like the first day we put them in it was just like [laughs] yeah ... it was hilarious. Yeah ... so he really ... really took to it.*

G: *and you're always thinking of new things all the time ... like ... you know what's the best way I could have the schedule for him? Like ... do I put another line beside it with ticks. I did that once before ... putting the ticks beside ... and I found it just too messy. So now it's just one line with the pics on it*

A few parents reported that they more able to understand what VSSs were once they better understood their child's individualities.

P7: *I suppose as a parent it kind of takes you a while to process the ... the information yourself once you realise that your child is in the same category. When I realised then that ... yeah ... you know ... the dislike of change ... or ... how to deal with ... you know spontaneous situations or whatever ... so preparing as much in advance ... I*

suppose that can be ... yeah the preparation for like any kind of a trip ... so the visual was kind of ... just kind of ... because that's really the main thing that's on offer ... you know ... when you talk about preparation ... it's I suppose that level ... what shall we say ... you know ... 7/8 ... it's the visuals ... planning of the schedules and it's the social stories.

As their understanding improved, they were more able to discuss the techniques with others. Almost all participants felt confident enough to make their own VSSs. Following the support, parents felt “more confident” (P3) to use them, with many showing the interviewer different samples of ones they had made. Some participants felt they were “quite technically savvy” (P2), where as others reported that as they went along, their use of technology improved. A few participants were happy for the professionals to make the visual tools for them but felt “confident” (P1) that they would be able to make them when the support would seize.

P1: *she's very good ... but then again ... that's a bit of laziness on my part because I have so much help at the minute . . . So that's the technology ... she's great at doing all that ... I won't say I don't know how to do it ... I just never tried it because she's done it for me.*

G: *a lot of them went in the bin [Laughs] because you know ... I didn't have a laminator ... never had a laminator. So ... some of them are more like ... just literally stuck onto backs of cardboard and were a bit ... you know ... not the best at all. And I actually still have one or two of them with the popcorn on it ... and things that I have kept. But ... now ... I'm an expert yeah ... laminate it out ... have it all ... you know the sizes and whatever.*

With some practice, most parents felt that the therapy tools were “simple” (P1, P6) to use, even though a certain amount of planning was required to put them in place. Most participants felt confident to use the therapy tools in their home or in public: “we feel good about it ... you know ... like ... it's not a problem” (P2), “I certainly have no hesitation using it” (P6). Although one parent did report that she would “hope the requirement for them is less” (P6) as her child grew older. Once an issue was identified, they were able to use

visuals with more confidence to address the problem, with immediate results. The use of visuals appeared to matter most when a problem was identified. Parents appeared able to assess situations and plan for them. When asked whether they still used visuals, one parent reported:

G: *No so much now. In the beginning I did have to ... because Chris had delayed speech ... and wouldn't use eye contact*

The time it took to make visuals decreased as their confidence, technology, and craft skills increased. Most parents used their phones, pc, as well as bought images to make the therapy tools. Some parents did report that they were unsure as to whether their child would still need the use of visuals in the future. Additionally, even though some parents felt they understood visuals, they did not always choose to use them. Finally, learning is an on-going process, with one parent reporting that you could never “become complacent” (P1) and stop learning.

4.7. Theme 3: Experiences of using Visual Support Systems

During the interviews, a number of pros and cons of VSSs were reported.

4.7.1. Barriers to using VSSs

In terms of the barriers, most parents reported that making visual tools can be a “time consuming” (P6) process requiring organisation, “an awful amount of thinking” (P2) and “planning” (P1), and “lots of pictures” (P2). Many pictures are available on the Internet making it harder for parents to select the right one:

P2: *I got over a million hits for a strawberry! . . . ok what strawberry do I use ... and then you could go through the whole thing of copying and pasting this and cutting it and then printing it and then it's too small ... or it's too big ... or it's ... oh my god ... you know ... and there was nights when it was just ... I can't believe I'm looking ... I'm still looking at strawberries*

Paying for images and other materials such as *Velcro* can be expensive and “hard to find” (P7). Additionally, symbols aren’t always universal, or clear, making them harder for the child to understand:

P2: *So what the Road Transport Authority might consider a symbol ... the Osbourne Book might not consider that the same symbol.*

One parent stressed the importance of making sure that both home and other environments are using the same pictures:

P2: *And that’s a problem that I find as well ... that if we use images here for particular things ... then school use something else*

Some parents felt that their children were becoming too reliant on the use of pictures, with one parent reporting she did not want her child to become “too dependent” (P7). Additionally, it was not always possible for parents to have visuals for every experience the child encountered:

P1: *we were saying we would do a story up for that ... and I was going ... god if we start doing a story up for that now ... do you know ... we’ll have stories coming out our ears ... you can’t have stories for EVERY ... SINGLE ... LITTLE change of situation.*

P6: *they can be a bit rigid. I mean like ... you could ... I feel sometimes like you could almost back yourself into a corner because it’s taken as a promise ... as opposed to possible. Do you know what I’m saying? So ... if you have an outline ... rough even as it is for the day ... and ... at the end of it you have something like McDonalds ... there are lots of times where that may not happen because something else has happened in the family ... or the car doesn’t work ... or ... but you’ve made the promise ... and like ... for a child with autism ... it’s very hard to explain why we can’t go to the ... because my car ran out of petrol ... or ... you know ... whatever it is. And there’s times where you kind of say you know ... I would have been better off saying nothing [Laughs].*

Some parents reported it can be hard to plan and use pictures for an event that has not occurred yet, especially if the parent themselves does not know the steps involved. Sometimes events occur unexpectedly making it hard for parents to have visuals at hand. The use of visuals can also make the child “stick out” (P1), especially as they get older. Visuals can also be associated with your child never speaking:

P3: *you're thinking ... you know ... you're saying I have to use these because you think my child is never going to talk sort of thing. So ... I think that was just more ... a bit of shock. But as I say ... once you kind of get your head around it . . . it's great.*

Furthermore, breaking down what might appear to be a simple task, such as getting dressed, can involve a lot of pictures:

P6: *even getting dressed ... or undressed. The amount of visuals ... which ... if you want to break it down to its lowest ... lowest ... lowest step. It's very hard to do it quickly. Like you and I ... that's where I started to get frustrated if you like ... because I felt ... in order to do one task of getting dressed ... and I broke it down to individual tasks ... I could have 15 images*

Two parents spoke of the pros and cons of using high-tech devices (e.g. *Ipad*) as opposed to low-tech devices (e.g. a picture). Using high-technology “takes away” (P2) from having to find an image, print and cut it. However, a child also has to have the “ability to catalogue in their mind” (P2) where that image is saved. Children require the “physical ability” (P2) to find images on a high-tech device. Lastly, having a high-tech device for one family member may be seen as giving “special attention” towards that child:

P6: *in this house ... if someone has an iTouch ... they all want the iTouch. So ... I actually stuck with ... because they did try on several occasions in school to get me to move to an iTouch ... and as I explained to them ... I need three of them. Because they will all want it ... and it won't be a communications device ... no matter how hard I try ... because ... if it's around his neck someone will use it as a weapon. It will be ... you*

know ... so I just said no ... we'll stick with the book ... it's boring the others don't want it.

Another disadvantage is that pictures aren't always "enough to fully express one's desires". "You can't have a visual for every single thing and no mind could store a visual for every single word or nuance of ... or ... and not even so much individual items ... but ... you know... *I feel sad* ... well ok ... you feel sad ... but there's still a huge amount of mind reading that has to go on then for ... to get to the root of . . . no visual ... or any amount of visuals can replace language" (P2). "It would be limited" (P6). Furthermore, if the child follows the instruction via the use of visuals, does he really understand the command or is it just coincidence? As one parent pointed out:

P3: *does he know where we're going ... or is it just he's just happy to go with the flow. So it can be hard to figure him out a little bit in that respect*

As children with autism can be very rigid, a slight change in picture "can just turn the whole world upside down" (P2):

P2: *we try and stick with the ... stick to the sort of symbols as opposed to branded ... because if they changed the colour of the packet of the biscuits ... or it's not there ... or you know ... toothpaste is just Colgate then she'll never use any other kind of toothpaste.*

Using and carrying a PECS book can be cumbersome and requires constant review. It does require "two people" (P2) when training the child to use it, which may not always be practical. Additionally, remembering to bring the book out of the house can be tricky, as well as the possibility of losing flimsy pictures.

P2: *You constantly have to be monitoring the book. So if we're going out ... we can't bring you know this gigantic catalogue of things ... so we have to think about what she might require with regards to communication to the particular place we're going. So in that sense*

we are limiting her own language ... but at the same time ... you know ... I suppose it's a downside

P6: *they're part of our life. Now at the beginning it took a while of having to train yourself to do that . . . it could quite easily get left behind ... if you're on a playground ... if you're doing something busy . . . It won't work unless it's kept up to date and maybe that's a downside*

PECS requires consistency. Finding items the child desires to encourage communication can be tricky, especially when his/her motivators are few (“he wouldn’t be particularly motivated by toys” (P3)). When the child’s most desired item is sweets, this can be a disadvantage and “you know when they ask you can’t say ... oh no ... no ... you can’t have that” (P2). Another downside of using pictures is that they can easily go “missing” (P3). “we used to lose lots of them” (P6). When used often, pictures tend to fall apart and need to be replaced (P3). One parent also described how it can be frustrating when not all family members take VSSs on board e.g. grandparents (P7). Lastly, one parent spoke of visuals being “the main thing that’s offered” (P7), wishing there was an alternative. Using language instead of pictures was also voiced as an opinion.

P7: *I suppose as a parent you feel frustrated because you would imagine that there is some other little magic cure that is there somewhere ... that maybe you're not being told about.*

P7: *I'd rather speak to my child ... and ... you know ... rather than use pictures ... but ... so maybe people are ... you know ... think that they are afraid of doing the wrong thing ... you know?*

4.7.2. Enablers to using VSSs

Visual therapy tools use the child’s strengths to work on their needs, with most parents describing their children as being very “visual” (P1, P6). Verbal messages can be too quick for the children to process, and therefore visual messages allow the children to give them time to process the message. Thus making them enjoyable for the child to use. As one parent stated: “it’s

amazing how taking the words out of it sometimes just makes it far more simple for people” (P6). Another pro is that other siblings in the home can use visuals. Thus including them (“I actually use it with the others as well” (P6)). They are also easy to access online (“all you need to do is Google it” (P6)). Some participants reported how after using visuals, they became more calm and understanding of their child’s needs as parents:

P6: *I mean if your child isn’t frustrated you’re less likely to be frustrated.*

Moreover, other people in the child’s life can understand visuals making it easier for the child to communicate. Additionally, it can be rewarding for other family members to feel like they can communicate with the child:

P3: *he was giving ... you know ... pictures and stuff to my sister and stuff ... for the milk and that ... or whatever . . . it’s just great when you can see him ... and even other people mention it when they come in and you know ... and he goes and gives them a picture and stuff ... you know it’s wonderful*

They also promote reading skills, as the word is also present on the picture: “it’s actually helped him recognize words” (P1), “he’s far more interested in the word than the image” (P6). Also ensures that everyone using the picture knows what the child means. Some parents noted other areas of development. These were: improved academic skills, feeding skills, cognitive processes, increased processing time, confidence, contentedness, and desire to communicate.

4.8. Summary

This chapter has presented the main findings of the study. The identified themes are: parent-professional partnership, perceived changes in abilities and skills, experiences of using VSSs. The final phase of data discussion and interpretation, in relation to the research questions, is presented in the next chapter: Chapter 5. This chapter presents clearer, analytic statements about the overall story that the themes communicate. It makes an important

contribution in that it provides additional information, not already researched, in relation to parent-professional partnership and the use of VSSs.

5.0. DISCUSSION, ANALYSIS AND INTERPRETATION

5.1 Overview

This chapter aims to implement the last stage of the thematic analysis approach (Braun and Clarke 2006), through discussion and interpretation of the major themes and sub-themes that emerged from the study, in order to address the research questions. Findings are discussed with a particular focus on the broader extant literature pertaining to parent-professional partnership, VSSs and autism. Three major themes were identified from the findings: parent-professional partnership, perceived changes in abilities and skills, and experiences of using VSSs. Sub-themes such as; shared planning and decision-making, and professionals' qualities are also presented and discussed here. A discussion of each research question is provided under headings to guide the reader through the discussion. This chapter also outlines the strengths and limitations of the study.

5.2. Aims of the Study

This study set out to evaluate the parental perspective and negotiation of responsibility with clinicians, as a way of meeting the needs of young children, with ASD, effectively. To reiterate, the aims of the study were:

1. To establish if parents participating in the study (who decided together with professionals that support around VSSs would be provided) experienced the support to be of value/benefit and to highlight any problems with the support to aid the development of future service provision.
2. To examine the effectiveness of the support provided by exploring and eliciting the views of parents of pre-school children with autism, about changes they perceived in their child's behaviour and communication skills as a result of the support.
3. To examine the effectiveness of the support by exploring and eliciting the views of parents of pre-school children with autism, about changes they

perceived in their own understanding of what VSSs are and how they are used. Also, to determine whether parents noticed changes in their own abilities to use VSSs following support.

4. To examine the model of collective empowerment, when planning goals and service provision around VSSs, through critical reflection.

The above questions are discussed in turn below. In order to recapitulate and set the scene, a brief description of how services were provided to the participants, prior to participating in this study, is presented.

Data was collected from parents of young children (under 6 years of age) who, on entering the early intervention service, had already been diagnosed with ASD. Once in the service, a team of clinicians would have been introduced to the family. The team generally consisted of a Speech and Language Therapist, an Occupational Therapist, a Clinical Nurse Specialist and a Psychologist. On some occasions, support from a Psychiatrist and/or Social Worker would have been provided. Following three informal assessment sessions (home or clinic visits), short-term goals would have been set up jointly with the professionals and family at a meeting.

Those parents, who identified together with the team that they would like to work on VSSs as one of their goals, were considered for this study. This allowed the researcher to address the research questions. Once goals were set up, the team provided support to the family around the introduction of the VSSs. Support was provided based on resources, family needs and priorities. Participants, who partook in the study, attended the service for 6-12 months. This is the average time a family tended to stay in the early intervention service, before moving onto a school-based team within the service, or another service. Data was collected from participants following the receipt of support within the early intervention service.

5.3. Question 1: Was the support provided, around VSSs, of benefit? Were there any problems?

One theme that emerged from this study was the relationship between the parents and the professionals following the VSSs support they received. This relationship shall be viewed in light of a “parent-professional partnership” definition where “there is full sharing of the unique expertise parents have in relation to their own children with the wider educational expertise . . . of professionals” (Beveridge 1999, p. 130). The two main subthemes that emerged were: planning and decision-making of goals around VSSs, and the qualities that the professionals demonstrated during the development of the relationship with parents. Participants in this study perceived that for the most part, the relationship between parents and professionals around VSSs was a partnership. However, whilst parents reported a mainly positive relationship, the idea of true, collaborative partnership working is debatable. The next section explores this theme in more detail.

5.3.1. Parent-Professional Partnership

In terms of the support provided, two main sub-themes emerged: shared planning and decision-making, and professionals’ qualities. The first related to the decisions made around planning goals, the quality of the support and training, and the amount of service provided. The second sub-theme related to the characteristics that the professionals demonstrated when working with parents. These are discussed in turn below.

Shared planning and decision-making

On entering the autism-specific service used in this study, children would have received a thorough assessment of need. Following this assessment, parents would have been provided with some information on effective therapy techniques. This information is usually also present at the end of assessment reports. The general recommendation is for professionals and parents to set common goals based on “assessment data that target the core deficits in ASD . . . considering family priorities when selecting intervention

goals” (ASHA 2017, p. 1). Whilst literature suggests the importance of considering family priorities, data revealed that most of the professionals working with the family recommended the use of VSSs. The idea of using visuals was somewhat unfamiliar to most parents. Some parents had heard about the topic prior to discussing goals with professionals but had not yet introduced the tools at home.

Given that most parents were unacquainted with VSSs, was it acceptable for the professionals to take the initial decision to work on VSSs? Was this decision made jointly? Looking back at Turnbull et al.’s (2000) definition of a partnership, a collaborative partnership is evident when families and professionals work jointly to reach mutual goals by sharing ideas, working together and having a good rapport. Having just entered the service the likelihood that partnership was evident is unlikely. Developing a relationship with families, and more so a partnership, takes time, ongoing work and is not built overnight (Kids Matter 2016). Additionally, families differ in terms of how they choose to be involved with autism services (Davies and Hall 2005). Researchers such as Case (2001) and Soan (2004), have felt that services have progressed from the idea of professionals being the “experts” and parents a less equal partner, to a model that recognises the importance of working with parents. However, there appears to be disagreement amongst researchers in relation to the most appropriate model of partnership that should be employed by professionals (Cunningham and Davis 1985). Robards (1994) suggests that professionals should provide an approach that best suits parents’ needs at the time. He recognises that parents at times may favour an approach, which requires the professional to be the “expert”. Therefore, the professional needs to recognise that partnership with parents is an active model, which occurs at many levels (Carpenter 2000). This may explain why professionals chose to provide parents with the information in the first place. Collecting information on professional’s perceptions of partnership working around VSSs would have enhanced the results obtained in this study. This is further discussed later in Chapter 6.

Providing parents with information on effective, evidence-based therapy techniques forms part of the duty of the professional (American Speech-Language-Hearing Association (ASHA) 2016). Although professionals are often under pressure when deciding what information and how to convey it to parents (Bruce and Schultz 2002), professionals need to identify and incorporate goals that consider the families' cultural and linguistic communication values and preferences (ASHA 2016). According to the *National Best Practice Guidelines* (The National Federation of Voluntary Bodies in Ireland 2010), meeting the family's information needs is a key priority and how these needs are met will impact on the subsequent stress and/or satisfaction levels of the parents. It is therefore essential to consider the individual family and to pace the information given in accordance to their needs. Consideration should be given to issues such as any current medical needs in the family, the potential levels of shock that this information will produce, whether the diagnosis is fairly recent, and whether the family has had time to process the implications of this diagnosis. There should be a balance between giving sufficient information while avoiding information overload. Tailoring the amount of information according to the individual parents' needs will mean giving sufficient information to those parents who seek further details and avoiding giving too much information to those parents who may feel overwhelmed.

Participants' reactions to the introduction of VSSs were also collected. Their reactions differed. Some were content with the professionals' decisions from the start. Others were more open to the idea once they obtained an understanding of the therapy tools and/or began to use them and see the effect. In order to try to explain why parents' reactions differed, it was felt important to consider how the professionals may have approached the idea of using VSSs. How the goal decisions were approached may have affected parents' reaction towards the use of VSSs. Additionally, how the parent was feeling at the time may have also affected their responses (Marchant 2015). It is also important to consider which professionals decided to work on VSSs.

As discussed in Chapter 2, disagreements and clashes amongst professionals can affect the way parents and professionals work together. Moreover, parents' perceptions of professional status cannot be ignored. The way parents responded to professionals' decisions might be attributed to the way they viewed professionals in terms of their status. The following quotes can be applied to this notion and summarise the importance of how professionals should be sharing information with parents:

"Giving the diagnosis of disability in a child to parents is a difficult and complex task that few relish. Done well it can reduce parental dissatisfaction and anguish; it can establish positive and important parent- professional relationships at a crucial time."

(Cunningham et al. 2002, p. 500)

"...and it's not just a sentence, every word is important because you are hanging on to everything they say and you will remember every word that they say, it sticks in your mind. They need to really plan their sentences and their words because this is going to stay with you for the rest of your life."

(Parent from the *Informing Families Focus Groups*, The National Federation of Voluntary Bodies in Ireland 2010, p. 7)

Research also suggests that how and when support is delivered, influences how well the family adapts and manages (Davies and Hall 2005). Obtaining information on how and when the information was provided may have added to this research. The thought of using a therapy technique with your child, when you have never heard of it, can be daunting for some parents. On the other hand, following professionals' recommendations because they are the "experts" is sometimes seen as necessary. Meeting the information needs of the family forms a key part in the parent-professional relationship (The National Federation of Voluntary Bodies in Ireland 2010), and therefore professionals should recognise its importance.

During the supposedly joint establishment of the goals process, some parents expressed how professionals felt "very strongly" (Parent 7) about using VSSs with parents' children, despite the parents feeling it may not have

been appropriate. Although VSSs are an effective therapy tool (Krantz and McClannahan 1998; Massey and Wheeler 2000; Morrison et al. 2002), and also keeping in mind that professionals have a duty of care to use the current best evidence in making decisions about the care of a child (Ross 2012), it is important to respect parents' views at all times. Engaging and involving parents in decision-making is recognised in the underlying principles of the *Statutory Framework for the Early Years Foundation Stage* (Department for Education 2014), *The Children and Families Act* (2014), and the *Special Educational Needs and Disability Code of Practice 0-25 years* (Department for Education and Department of Health 2015) in the United Kingdom. Whilst there is evidence to suggest that the therapy techniques are useful (Dauphin et al. 2004; Johnston et al. 2003), professionals are required to select approaches that are appropriate for the parents they are working with. A particular approach may not always be suitable for everyone, and therefore one that fits in with the professionals' goals and the needs of the family is more liable to attain measurable outcomes (Lloyd 1999). Therefore, effective practice does not only rely on the professional selecting an evidence based therapy technique, but rather "involves a practitioner bringing their own knowledge and skills together with best quality evaluation research to make a decision about selecting which programme or intervention is most appropriate to the parents and children they are working with" (Parenting UK 2017, p. 1).

On the other hand, professionals may argue that time constraints do not always allow for such discussions with parents. Glaziou and Haynes (2005) suggest that research that is intended to change practice is sometimes underused. This is because of lack of understanding or lack of time on the part of the practitioner. Interestingly, a few parents reported how some professionals weren't so informed on the benefits of using VSSs and therefore not so much "in favour" (Parent 2). Research tends to suggest that services should be parent-centred where strong importance is placed on discovering, valuing and reacting to parents' perceptions, understandings

and beliefs. This involves always bearing in mind the viewpoints of parents and appreciating that each parent/carer will have different concerns, requests and hopes, so that a 'one-size fits all' method of service delivery is not suitable (Department for Education 2010).

Once goals were established, the quality of the training and support that parents received was felt to be, for most, helpful, specific to their child's needs and useful. It allowed parents to clarify any questions they had, such as why and how VSSs are used. Professionals shared and communicated information with parents by using a variety of methods, such as modeling and group training. Therefore, taking into account the various needs of the families. The level of commitment that the professionals demonstrated when providing parents with information, to ensure quality of service, may explain this. This matches with research suggesting that most professionals generally do want to provide a good quality of service as it is in their nature as health professionals (National Health Service 2017). They are committed to partnership in order to meet the needs of the clients and develop services. Commitment may be explained by the length of time the professionals worked for in the service. Whilst there have been some changes, most of the staff working in the early intervention service have been in employment for over 7 years. In terms of partnership length however, parents' perceptions have been collected following a relationship period of between 6-12 months. Partnership takes time to develop (Carnwell and Carson 2009) and whether this was truly evident is up for debate. Indeed, it is clear from parents' views that whilst the support was valuable, more regular support was sought.

Whilst the quality of the information around VSSs was satisfactory and helpful, some parents made reference to the need for additional, regular family support. Why was more regular support required? According to Whitaker (2002) and Stoner et al. (2005), parents are keen to do what they can to help, and there is a very conscious thirst on their part to learn about autism and intervention strategies they can use to promote their children's

development. However it is also possible that, in the aftermath of diagnosis, the quest for information may actually be a short-term strategy for managing their overwhelming emotional needs (Beresford 1994; Lazarus and Folkman 1984; Whitaker 2002). Parents may feel that asking for more information is acceptable, as a way of coping with the diagnosis, while asking for emotional support might not be appropriate (Seligman and Darling 1997). Whether the support requested is momentary or extreme, sought immediately or gradually, may empower parents to manage daily events that may add stress (Nachshen and Minnes 2005; Starke and Möller 2002; Stoner et al. 2005). A parent's satisfaction with support can be a sign for determining the way parents are adapting to their child's diagnosis and the stress associated with it (Dale 1996). Research suggests that parents who report positive attitudes and experiences to the support they received felt well supported along the way (Mandell and Salzer 2007). Therefore, the professional is required to understand that parents will have different needs at different times, and these requests need to be respected (Green et al. 1999).

A delay in receiving services was also reported by one parent, which may explain why that parent did not feel as supported. The struggle to receive consistent and applicable information after diagnosis also supports previous findings by Murray (2000). Unfortunately, service provision is not always determined by families' needs but rather resources. Most families would have received support from professionals on a weekly basis, sometimes over a 6-week period, depending on the needs of the family. Experience, however, has revealed that resources will often determine the amount of support delivered. Therefore this may also explain the lack of support felt on that parent's part. Hurst (1997) suggests that professionals should not ignore parents' needs, but rather they must be flexible in the way in which they meet these needs. Lack of resources, due to for example financial pressures, is a common barrier often described in effective partnership working (Banks 2002). It is suggested that managers, directors and practitioners within services reflect on their partnership working to establish more effective ways

of working with parents (Joint Improvement Team 2009). However, there is also a requirement for change at a governmental level. Despite policy suggesting the need for partnership working (HSE 2010a), there needs to be focus on reform in terms of the structure of services and the way resources are allocated.

Professionals' Qualities

Parents were appreciative of the qualities demonstrated by professionals when working on the therapy techniques. These included: being knowledgeable, understanding and supportive. Successful partnerships often depend on the professionals' interpersonal skills (Park and Turnbull 2003). Literature pertaining to these interpersonal factors is mainly qualitative and widely available (Dinnebeil and Rule 1994; Dinnebeil et al. 1996; Summers et al. 2001). The data analysis carried out in this research study resonates with the studies carried out by Dinnebeil et al. (1996) and Summers et al. (2001), who identified personal qualities as being important to effective partnership working, such as: friendliness, integrity, commitment, communication skills, sensitivity to parents, clarity, and respect. Parents valued professionals who took the time to make therapy tools for the child and family, demonstrating an ability to be flexible, supportive and understanding of the family's needs. However, whilst positive qualities were identified, a few parents spoke of one factor that was indeed absent: the lack of collaboration between health and education services.

Participants spoke of the difficulties they encountered when trying to convince their child's school to use the therapy tools. Indeed, Blue-Banning et al. (2004) reported that some parents often have difficulties when communicating with school staff. Additionally, Soodak and Erwin (2000) found that schools were not always open to parents' ideas and techniques that work for their child. Participants felt that support from the health professional, to ensure all of the child's environments were using the therapy tools, was lacking. Parents would have appreciated backup from the

professionals to convince the schools to use the therapy tools. There appears to have been a lack of communication between health professionals, education staff and parents. Indeed many government policies and procedures highlight the need for collaboration between health and education services in both the UK and the Republic of Ireland (Department for Education and Department of Health 2015; HSE 2010b). It is not reasonable to say that all parents were dissatisfied however. One parent did report the positive impact it had on her family when her Speech and Language Therapist acted as a link person between home and school.

Lastly, parents reported that at times the information provided was delivered quickly. Some felt professionals assumed parents knew what they were talking about. According to Carnwell and Carson (2009, p. 6), “a partnership is a shared commitment, where all partners have a right and an obligation to participate and will be affected equally by the benefits and disadvantages arising from the partnership”. Therefore, if parents felt the information was delivered hurriedly and without taking into consideration what the parents knew or did not know, did professionals demonstrate effective partnership working? On the other hand, a partnership requires two people and without feedback from the parent, is the professional responsible for not knowing whether the information was being delivered appropriately, both in terms of promptness and content? It is hard to establish why the professionals did not meet the needs of some parents when the information was delivered. There could be a variety of reasons. Firstly, personality clashes can present a significant barrier to a partnership. Without mutual trust and understanding both partners cannot fully disclose their concerns (Greater Manchester Centre for Voluntary Organisation 2008). Therefore, it is key that both partners are aware of each other’s concerns and this can only happen if there is open communication between partners (Pinkus 2005). Mutual trust and respect is key to partnership working and should be considered attentively (Labonte 1994). Time might have also influenced why professionals chose to deliver information in a manner that did not consider

parents' needs. Whilst 'time' appears to be a common theme amongst the concept of good partnership working (Tones and Tilford 2001), resources will often influence how much time a professional has to be able to work in true partnership with a parent (Stahmer 2006). Professionals and service managers need to recognise that "the productivity of a partnership is higher than if each partner worked separately as a result of each partner doing what they do best . . . real partnerships work and are worth the time and effort" (Greater Manchester Centre for Voluntary Organisation 2008, p. 2).

5.4. Question 2: Did the support result in any perceived changes in their child's behaviour and communication skills?

This question relates to the second theme that emerged from this study, 'perceived changes in abilities and skills'. One of the sub-themes related to 'changes in children's skills'. All parents reported perceived positive change in their children's skills following the use of VSSs. The three main areas of change were: behaviour, communication and pragmatic skills. Improved understanding of instructions and events, and further developed expressive and social language skills were reported. Most parents observed more desirable behaviours. These findings resonate with the literature (Krantz and McClannahan 1998; Massey and Wheeler 2000; Morrison et al. 2002). Krantz and McClannahan (1998) found that following the introduction of visual schedules using photographs, three boys who participated in the study with poor verbal skills, had developed and maintained spontaneous social exchanges after the study. Baseline data was collected prior to the introduction of the study. On reflection, obtaining baseline data prior to carrying out this research study may have added to this research. However, the aim of this research was to examine parents' perceptions of change as opposed to monitoring change. Additionally, time limitations added to this decision. Though a baseline could have been conducted before commencing this study, "a project may begin to affect baseline conditions prior to the formal project start" (IFRC Planning and Evaluation Department 2013, p. 11). For example, because this study was carried out with parents

following 6-12 months of intervention, participants may have deliberately provided inaccurate information at the start of the project, resulting in a baseline that underestimates the effect of the study. Additionally, respondents may have failed to provide accurate information at the start of the study, out of fear that services would be limited if they portrayed their children as having fewer difficulties. Nonetheless, the positive changes that were reported corroborate with quantitative research studies on the effects of VSSs for children with ASD.

5.5. Question 3: Did the support result in parents perceiving an increased understanding of VSSs and changes in their ability to use them?

Results from this part of the study revealed positive perceived changes in terms of knowledge acquisition, practice of and the use of VSSs. This relates to the second sub-theme 'changes in parents' abilities and skills' under the theme 'perceived changes in abilities and skills'. Parents reported increased understanding of VSSs and ability to use them following the decision to work on the tools and the support provided. None of the participants used the incorrect terminology when describing VSSs, demonstrating an increased understanding of the terms. During the interviews, a good understanding of the therapy techniques was also recognised. In terms of behavioural intentions, research appears to demonstrate that there is a strong correlation between intending to carry out change and then actually carrying it out (Sutton 1998). Once parents decided to implement VSSs, they then went on to actively introduce them with their children. Looking back at the decision to work on VSSs, in section 5.3.1., the following quote may explain why parents chose/chose not to implement VSSs:

for every person, behaviour is driven by their emotions and feelings, and by their thoughts and beliefs. One cannot act unless one has premises on which to initiate the action, and a context in which to do it. There is always a reason why we do what we do: actions do not just

spring up, completely without cause. The causes are our feelings and emotions, and our thoughts and beliefs. (Marchant 2015, p. 1)

Therefore, parents' decision to work on VSSs may be due to how they were feeling, and how well they were coping with the diagnosis, as discussed earlier.

Following opportunities to practice and create their own VSSs, parents felt their knowledge increased over time. Most reported also adapting the tools to suit their child's needs and family lifestyle. Some parents felt that once they became clearer about their child's needs, they were more able to understand what VSSs were and how they could be used with their child. Increase in understanding of the tools meant parents were able to pass on the information to others. Following the support parents felt more confident to use VSSs and make them. Some parents reported that they appreciated when professionals made the VSSs for them. They felt confident using them without the professionals' support. Visuals were mostly used during problematic situations for the child and/or parent. Parents gained experience assessing situations and planning the use of VSSs for that situation. Parents did not rely on visuals all the time, but only when they felt they were needed. As they became more experienced in making the visuals, the time it took to make them decreased with parents reporting an increase in technology skills. Parents reported how they learned as they went along. These findings are consistent with the literature suggesting that following support, parents were more able to resolve the daily difficulties and struggles that are part of family life with a child with an ASD (Whitaker 2002).

The Stages of Change model (Prochaska 1979; Prochaska and DiClemente 1983; Prochaska et al. 1992) can be applied to parents' change in behaviour. This model identifies five stages that people generally go through during a behaviour change. These are: 1) pre-contemplation, 2) contemplation, 3) preparation, 4) action, and 5) maintenance. How one moves through these stages is dependent on self-efficacy and the attitudes of the person

concerning the pros and cons of the behaviour that is to be changed (Armitage et al. 2004). Indeed, high level of self-efficacy is often seen as key for coping with the needs of children with ASD (Salas et al. 2017). Therefore, in applying this model to the behaviour change around the use of VSSs, in the pre-contemplation stage parents may not intend to introduce the therapy tools. This is often associated with the cons of changing behaviour. As discussed, a lack of understanding of the therapy tools, stigma, parents' adjustment to the diagnosis, or observed improvement in their child's skills, may be reasons as to why parents were against/pro using the VSSs. During the contemplation stage, parents are more able to consider the pros and cons of why the therapy tools should be implemented. The next stage, preparation stage, the parents would have been ready to take action and therefore small steps taken towards change. Therefore, feeling ready and prepared, and starting to change behaviour. Once VSSs are used, they are continued to be used during the action stage, and may also begin to modify the way they are being used. Throughout the maintenance stage, the person intends to maintain their behaviour change. Moving onto the termination stage where the behaviour change has occurred to the full, with no desire of returning back.

It is acknowledged that this model does not provide reason as to why some parents' behaviour changes more effectively or quickly than others. It also fails to consider the families' needs as a whole, within the context of the systems of relationships that shape that parent's environment (Paquette and Ryan 2011), linked to Bronfenbrenner's Ecological Systems Theory (1979). For example, factors such as the relationship parents have with their extended family which might influence why they choose/do not choose to use the therapy tools. Some parents did describe how they did not always choose to use visuals for reasons such as time, stigma and the idea that their child would be dependent on them. Some worried about whether their child would still need them in the future. Additionally, it is hard to determine the stage parents were at when carrying out this research, and therefore a tool to

evaluate parents' stage of readiness and change may have been helpful when determining support. Having a tool that measures how ready parents are to introduce VSSs would provide the practitioner with a quick and relatively easy way to identify whether VSSs are suitable, reducing time and avoiding possibly difficult conversations. This however was not the purpose of the study. The aim was not to examine parental perspectives using objective measures, but rather parent-reported outcomes as this was lacking in literature. Ultimately, partnership working is about having open discussion and communication between partners (Carnwell and Carson 2009). Having a tool to measure a parent's readiness places the professional in power, thus power is not shared which is essential to an effective partnership (Wildbridge et al. 2004). The Stages of Change Model however has been useful in trying to understand parent's responses. Parents may require different levels of support when implementing change (Carpenter 2000). Lastly, parents' perceived ability to change their skills in order to manage better can have an indirect impact on their child's progress (Osborne et al. 2008), and for this reason the positive changes that were reported are significant.

5.6. Experiences of using VSSs

Another theme that emerged from this study was participants' experiences of using VSSs. This was not directly related to any of the research questions. However, the richness of information collected cannot be ignored. Qualitative research on parents' experiences of using VSSs is somewhat limited. Examining parents' experiences of using VSSs was considered invaluable for refining practice. Parents shared both positive and negative experiences of using VSSs. Some of which corroborate with literature (Hayes et al. 2010; Hirano et al. 2010; Hodges et al. 2006). These are discussed below:

5.6.1. Enablers to using VSSs

The benefits of VSSs, as identified by the parents in this study, were:

1. Other people in the child's life can understand visuals. This makes it rewarding for both communication partners;

2. Promote reading skills;
3. Improve academic skills;
4. Improve feeding skills;
5. Improve cognitive functioning;
6. Increase confidence;
7. Increase contentedness;
8. Increase the desire to communicate;
9. Allow time for the child to process what is being said;
10. They work because children with ASD are visual learners;
11. Enjoyable to use;
12. They allow parents to have a better understanding of their child's needs;
13. Can be used with siblings in the home environment.

This in-depth and rich information regarding the benefits of using VSSs is currently limited. Research tends to focus on the effectiveness of VSSs as opposed to the perceived benefits proposed by parents, and for this reason the above is important as it allows practice to advance (Baker 1997). These positive, perceived benefits increase the likelihood of the parent pursuing a given course of action, in this case using VSSs, as the belief is that the action of using them will lead to a desired result (Bandura 1997; DeVries et al. 1989). The desired result is that their children's skills will improve, which is ultimately what parents of children with ASD want (Gallagher 2016). Additionally, parent led therapy has been shown to improve skills for both parents and their children (Pickles et al. 2016). By considering the benefits of using VSSs, both professionals and parents working with children with ASD can understand that from these collected perspectives, VSSs are beneficial due to the above advantages.

Firstly, visuals can be understood and used by most people (Bondy and Frost 2011), as opposed to sign language (Bogdashina 2005), and for this reason are advantageous. They can be used in the home environment with

siblings, without having a negative effect on other family members (Middletown Centre for Autism 2018). Research has also suggested that using visuals can improve reading skills. By using words and pictures together, text is reinforced (Carney and Levin 2002). Interestingly, most children with ASD tend to demonstrate average word and non-word reading skills, however poor comprehension is often demonstrated, “consistent with a hyperlexia reading profile” often seen in children with ASD (Nation et al. 2006, p. 911). It is therefore not surprising that pairing pictures with words can often result in increased comprehension skills (Courter 2011). There are numerous research studies that have established the influence of visual aids in learning. For this reason, the perceived benefit of improved academic and cognitive skills is not unforeseen. Using VSSs has been shown to improve cognitive functioning (Cohen and Sloan 2007). One study asked students to remember several groups of three words each, for example, ‘cat’, ‘car’ and road. Those who attempted to remember the words by means of repeating the words many times did not do well when asked to recall the words. In contrast, those who made visual associations with the words, such as imagining a cat driving a car down a road, had notably better recall (McDaniel and Einstein 1986). Visuals can reduce learning time, improve understanding, augment retrieval and increase memories (Meier 2000; Patton 1991; Schacter 1966). Additionally, verbal messages can be too quick for some children with ASD (Spears and Turner 2011). Therefore by using visuals, the time given to the child to process what has been said to them is increased.

The above outcomes make complete appreciation of parents’ views. It is not surprising that parents of children with ASD will often describe their child as being “very visual”. Generally, people tend to receive significantly more information from visuals than any other of the senses (Hyerle and Yaeger 2007). Indeed the area of the brain concerned with processing visual images is larger than that used to process words (Milner and Goodale 2006). This also explains why we live in a society where most of the information around

us contains a visual nature (Berger 1989), for example signs, menus with pictures, billboards etc. Additionally, research by Kana et al. (2006) has shown that for people with ASD, work based tasks are processed in the visual parts of the brain. Grandin (1995), a known author with autism, supports the use of visuals amongst people with ASD. She describes herself as having a visual learning style. She describes how the use of visuals has improved her understanding of language.

Parents not only described how they felt their child's behaviour and communication skills improved, as described in section 5.4., or cognitive skills as described above, but also their feeding skills. Giving children an opportunity, a 'voice', to ask for food items may explain these results. Feeding difficulties in children with ASD is not uncommon. Recent research indicates that many children with ASD demonstrate limited and fixed eating behaviours (Ledford and Gast 2006; Fodstad and Matson 2008). Research in relation to the use of visuals to improve feeding skills is somewhat limited. Use of visuals have however been recommended as an effective way for improving feeding skills (Twachtman-Reilly et al. 2008). Further research in the area of feeding skills and the use of visuals is advocated. Allowing the child to request for desired items using visuals provides the child with an opportunity to 'voice' their thoughts. Additionally, it increases a child's desire to communicate further (Bondy and Frost 1994) and improve overall confidence and contentedness, which is key to continued learning (Gonzalez 2009). Presenting a therapy tool that is fun to use, easy to understand, and positively reinforced is more likely to be effective and used again (Eisler and Frederikson 1980).

Lastly, parents described how following the use of VSSs, they were more able to understand their child's needs. "Visuals can promote appropriate, positive ways to communicate" (Loring and Hamilton 2011, p. 1). Parents often want to be able to support and communicate more effectively with their children (Hanen 2018). If parents are more able to communicate with their

child because of improved communication skills, and understand their child's needs in more detail, parents' stress levels are consequently reduced. Research indeed suggests that child symptom severity is frequently the strongest predictor of stress levels amongst parents (Neff and Faso 2014). In conclusion, the collected data appears to resonate with current quantitative research related to the effectiveness of VSSs. Ultimately, "parents know their child best" (Department for Education 2011, p. 41) and approaches which:

involve professionals working together with parents right from the start to support the child's learning and development can have huge benefits for the child's achievement and wellbeing. Learning from parents and sharing information with them can give professionals a much better understanding of how best to support a child. (Department for Education 2011, p. 34)

According to the 1978 *Special Educational Needs: Report of the Committee of Enquiry into the Education of Handicapped Children and Young People* (The Warnock Report), "parents can be effective partners only if professionals take notice of what they say and how they express their needs, and treat their contribution as intrinsically important" (Department of Education and Science 1978, p. 151). Their views therefore cannot be ignored.

5.6.2. Barriers to using VSSs

Whilst parents identified the advantages of using VSSs with their children, disadvantages were also discussed. Some of the barriers identified were an unexpected result, thus creating new knowledge that hadn't previously been reported in literature. A list of significant barriers that were identified is presented later. Additional barriers are presented in Table 5. The barriers presented in Table 5 are discussed briefly as some literature in relation to these is already present. It was felt that the barriers not currently reported in

literature would be presented in more detail demonstrating a significant contribution to knowledge.

1. Making VSSs is time consuming, tiring, and requires organisation and planning;
2. Materials can sometimes be expensive;
3. Symbols are not always universal or clear making them harder for the child to understand;
4. Children may become reliant on visuals making change even more difficult to manage;
5. It is not always possible to use pictures in all environments – so consistency is not always possible;
6. Planning for an event that has not occurred yet can be difficult;
7. Sometimes events are unexpected so the parent cannot always plan;
8. Simple activities need to be broken down into many pictures;
9. A picture cannot always fully express one's desire;
10. Requires a lot of mind reading;
11. Changes in pictures can be very hard for children to manage;
12. PECS requires two people to use and requires consistency;
13. It can be hard to assess whether the child really understands the picture being presented or whether he is just going with the flow;
14. Some low-tech devices can be cumbersome to carry and require constant review;
15. Pictures can get lost, flimsy and need to be replaced often;
16. Parent needs to remember to bring the VSSs out of the house when travelling;
17. Selecting the right picture for your child can make it confusing giving the vast array available on the internet.
18. Can be hard to find motivators. Sweets are not always possible;
19. Can be daunting to use.
20. Frustrating when not all family members use them.

Table 5. List of additional barriers identified.

Most of the above data collected, corroborates with that of Hayes et al. (2010), who also documented a series of disadvantages for using VSSs. The difference is that their research fails to describe whether views were collected from parents or professionals working in the field. However, Hayes et al. (2010) raise a noteworthy argument, which is that when VSSs are recommended, they are usually based around the needs of the child as opposed to the family. For this reason, it is important to note that whilst there

is evidence to suggest their effectiveness (Bondy and Frost 1994; Ben Chaabane et al. 2009; Silverman 1995), the above barriers need to be considered with the family in mind. Coping with a diagnosis of ASD can be hard for some parents (Dunn et al. 2001) and therefore recommending a strategy that might not be easy to use for some, despite documented evidence, can result in added stress. It is therefore important that professionals inform parents of the potential advantages and disadvantages of using VSSs, so that they can take an informed decision, as ultimately partnership working is only successful if both parties consider each others' needs (Dawe 2006).

Despite their remarkable advantages, as discussed in earlier chapters, use of VSSs continues to be problematic for many parents. There are a number of difficulties to using these therapy tools, which are mainly paper-based. VSSs are resources to support children to improve both their communication skills and their social skills, yet these resources need to be continually adapted and modified to suit the child, who besides being unique and individual is also continually changing and developing. Parents have commented on the difficulties they face when creating and using these resources. They have cited the expense involved in purchasing the materials and last but not least the difficulty of monitoring how effective these tools actually are. The same visuals must also be used consistently across the different settings (Middletown Centre for Autism 2008).

Significant barriers were identified throughout the study. There were:

1. Can make the child stand out;
2. Can “disable” a child – associated with child never speaking;
3. Lack of communication between different environments may result in different people using different symbols;
4. Associated with this extra work that a parent has to do to manage their child – as opposed to a simple fix;

5. They are not always the answer to all the child's problems – do not always work.

It is not surprising that some parents have expressed the opinion that using visuals can make their child 'stand out' or 'disable' them. Even without the use of visuals, children with ASD can appear 'different' due to the way they view and respond to the world around them (Middletown Centre for Autism 2018). Despite the fact that visuals can be used by all, for example in a mainstream classroom, and can be made to look unnoticeable, parents have reported the stigma associated with the use of visuals. Children with ASD may not appear physically different to other children, although they may display unusual behaviour patterns or problem behaviour (Sarris 2015). Onlookers may therefore mistake a child's 'autistic' behaviour for poor parenting, lack of self-discipline or even a mental illness.

Adding a therapy tool that makes the child 'stand out' further in the community can be hard for parents to accept. However, what about those parents in the study who did not mention stigma? Is stigma associated with accepting a diagnosis? In Great Britain, Ginny Russell and Brahm Norwich (2012) conducted a study on two groups of parents – one group had accepted an ASD diagnosis for their children, while the other group had consciously avoided their children being given a diagnosis. The parents in the latter group resisted having their child assessed and 'labelled', although they had been told by professionals that their child might have ASD. The study discussed how often parents have to deal with trade-offs when having their child diagnosed. On the one hand, having a diagnosis may invite shame, prejudice, and bereavement due to loss of "normality". While instead, having a diagnosis may result in specialist services, therapies and educational services that will impact positively on the child's well-being. The parents who refused diagnosis - the 'avoiders' - often mentioned shame and rejection as a key worry. As one parent described, "When you apply perhaps a medical label it all seems to be, to the outside world it seems to be a lot

more serious, a lot more scary . . . they start thinking, oh well, maybe I don't want my child to play with him." Other parents were concerned that people would label individualities that were purely unconventional or distinctive as "abnormal" traits.

Whilst the main focus of this study concerns partnership working amongst parents and professionals working in a specific service, it is also evident that partnership working is required across various settings (Carnwell and Carson 2009). Lack of communication amongst different environments (mainly school, home, and clinic) was reported. A different organisation providing different services is not beneficial to partnership working. In Ireland, multi-agency working continues to be emphasised in government policy (Department of Health and Children 2000; Department of the Taoiseach 2006).

Professionals must remember that VSSs are there to help the child, yet they must be user-friendly and supportive to the caregivers' needs. They must not place an extra burden on the family, who is already being challenged to implement an augmentative communication system. Families of children with disabilities often face challenges that other 'typical' families do not (Goldsmith and Leblanc 2004). They lose on sleep, have to spend time away from work, and have to travel to attend appointments (Tartaro 2005). Dawe (2006) suggests that the success of families using alternative and augmentative support systems depends to a large extent on how comfortable and engaged they feel with the process. For this reason, it is important that the professional considers parents' views, when deciding to implement VSSs. Additionally, whilst high-technology devices outweigh some of the issues, involving persons with ASD and their family in decision-making regarding the best VSSs, throughout the assessment and intervention process, is paramount. Bailey et al. (2006) reported that lack of family input when deciding on a VSS is a significant reason as to why some families abandon such support systems.

It is also important to consider that VSSs are a therapy tool used to support the development of a child with autism. However, it is recommended that they are used as part of an eclectic approach; incorporating a variety of principles and philosophies to create the ideal therapy programme to meet the specific needs of the child. VSSs can be used together with other therapeutic techniques. It is imperative that parents and professionals understand that VSSs are 'not always the answer' and it is up to the professional and parent together to offer an approach that best meets the needs of the child.

5.7. The model of collective empowerment

The last issue that this study aimed to examine was the model of collective empowerment employed by the service in question. Most of this was examined in the research collected above. It appears as though parents, for the most part, felt that the professionals worked with them in a collaborative manner. At times, however, the parents working with the professionals faced difficulties and challenges. 'Parent-Professional Partnership' has been described as a process where both professionals and parents communicate successfully and problem-solve in collaboration (Dale 1996). It is depicted by characteristics such as mutual trust and respect (Turnbull et al. 2000). In the Republic of Ireland, working in partnership with parents has been recommended as a successful method of providing service to children with special educational needs, such as ASD (National Parents Council Primary 2004). Working in partnership with parents is an effective and important method of delivering services to children and their families (Boot and Macdonald 2006).

Notwithstanding some literature suggesting that parent-professional partnerships often fail (Pinkus 2003), the majority of the participants indicated that overall, there was a positive relationship between the parents and the professionals. Whilst several characteristics for effective partnership working are often recommended (Turnbull et al. 2000), and partnership working is

seen as important (Dale 1996), research is limited on advice regarding the amount of collaboration required in order for there to be true partnership. Additionally, research around parent-partnership during the implementation of VSSs is scarce. Although it is suggested that the professionals in this study did exhibit certain characteristics, which helped parents to work effectively with the professionals, it is hard to establish whether parents perceived their relationship with professionals as a true partnership. Whilst qualitative research on partnership working tends to identify the interpersonal skills required for partnerships to work (e.g. Park and Turnbull 2003), data around the degree to which parents perceived their relationship with professionals, as a partnership is limited. This is an area deserving research, as it may be useful in an environment where partnership models of service delivery are implemented and require evaluation. Nevertheless, this research study suggests that the service's attempt to work successfully with parents has had a positive effect on the relationship of most parents.

It should be recognised that this research study encompasses the views of a relatively small sample of parents. Therefore, it is difficult to generalise these findings beyond the limits of this study. Sample size and generalisation of findings are discussed in more detail later. Subsequently, considerably more research needs to be carried out, to obtain the opinions of a larger sample of parents working with professionals in an ASD service. However, the results are consistent with the work of Bailey et al. (2004), who found that most parents were satisfied with the relationship they had with early intervention professionals. Professionals working in the field of ASD, who have identified the need to introduce VSSs, and are willing to work in partnership may wish to consider the above data when working with parents. The difficulties acknowledged by the parents also emphasise the need for professionals to re-examine their methods of working when introducing VSSs. It is recognised that training in partnership working is required. This should further develop the interaction and relationship with parents, thus promoting parent-professional partnerships.

5.8. Strengths and limitations of the study

Several strengths and weaknesses come to the fore in evaluating this research. The first strength of this study has been the exploration of the perceptions of parents in a particular early intervention service and therefore this should provide valuable information for those involved in the delivery of this specific service. Additionally, the combination of a focus group and individual interviews ensured richness and a breadth of data to be collected (Cohen et al. 2000; Lambert and Loiselle 2008).

In order to assess the quality of research, three areas are generally considered. These are generalisability, validity and reliability (Bryman 2001; Sarantakos 1998). However, these mostly relate to quantitative research, and therefore using the alternate principles of trustworthiness and authenticity for assessing qualitative research (Bryman 2001; Sarantakos 1998) is considered. This research study was fundamentally qualitative in nature and the data collected is reported as a narrative (Lodico et al. 2006). "Researchers who are using interpretivist paradigm and qualitative methods often seek experiences, understandings and perceptions of individuals for their data to uncover reality rather than rely on numbers of statistics" (Tanh and Tanh 2015, p. 24). Reality is therefore discovered through participants' opinions and experiences. Therefore, the degree to which the data presented here is trustworthy in reporting the findings of this study is the main concern. Interpretivist researchers believe that understanding the context in which the form of research is conducted is vital to the interpretation of data obtained (Willis 2007). As the researcher worked for the service in question for many years, experience and a close relationship with parents has added to the interpretation of the results. Further understanding around the issues concerning VSSs was lacking, both in terms of research and personal professionalism, and therefore influenced the purpose of this research study. The central belief of an interpretivist paradigm is that reality is socially constructed (Tanh and Tanh 2015). Collecting data and forming multiple

understandings of the participants' individual views answered research questions. Limitations are discussed in more detail below.

5.8.1. Case study approach and sample size

This study employed a case study approach; this was considered an appropriate method to use in order to understand parents' perceptions of VSSs and the support provided. The study was comprised of ten participants attending a service in the Republic of Ireland and although it provided a valuable picture of parents' views in a specific context, generalisability to other regions or services is impeded (Flyvberg 2004; Gomm et al. 2000; Silverman 2005; Yin 2003). Furthermore, it is understood that due to the small sample size, parents' views may not be representative of the wider population of parents of children with ASD. A case study approach presents limitations in relation to generalisability of findings. However, this is expected in qualitative research (Murphy 2001) and goes beyond the scope of the study. The aim is not to generalise, but perhaps to make some small generalisations (Stake 1995), which may resonate with other professionals and parents working in the field of autism. It is acknowledged that the perceptions collected are representative of a small sub-section and therefore results cannot be applied to the wider population. However, through experience, the role of services in meeting the needs of parents and children with autism are known to be similar across settings due to the nature of the disability and the major impact it has on the health and wellbeing of families. Additionally, a case study approach with a small sample, allowed the researcher to collect in-depth information of the issues that arose (Mason 1996).

It may be contended that the small number of participants who agreed to participate in the interviews assumed passive roles and therefore this may have been different if more action-oriented participants took part in the study. Even though participants were assured that all information collected was anonymous and confidential, participants may have still felt reluctant to

disclose any negative information, with the fear that future services might be affected. The selection of participants was based on purposeful selection of participants that met a series of criteria. All parents of children with ASD were invited to participate in the study. However, a series of criteria had to be put in place in order to answer the research questions. Another limitation is that the views collected were only representative of those parents who are likely to engage with professionals/researchers. This means that the experiences of 'hard to engage' parents might have not been collected (Bonevski et al. 2014). It could be argued however, that the interviews also provided parents with an opportunity to discuss their concerns, with the hope that services will change. Not knowing for certain whether the participants were sincere in their responses can be seen as a weakness of interviews (Walsh and Wiggins 2003).

An additional limitation is that the study has relied on the parental experiences and attitudes of a sample of parents whose children had a wide range of difficulties, which is a concern when studying ASD as it encompasses a wide range of severity and symptoms. Responses of participants from different backgrounds were not compared, as this was not relevant to the purpose of this research. Collecting data on parents' cultures and values and how this related to their responses may have added to the research. However, because parents represented different views it was possible to compare their respective perspectives. Additionally, parental involvement in the collaborative model of partnership working would have been better understood if the views of professionals were obtained. However, due to time constraints this was not feasible. It is also acknowledged that views gathered from a larger number of participants would have increased the validity of the results (Robson 2002). Whilst the sample size may be considered a limitation, for professional doctoral studies, a sample size of ten is considered appropriate (Buckley and Delicath 2013). The aim of this study was to collect in-depth, qualitative considerations of parents' views within a particular service, and therefore a small sample was deemed suitable.

Another strength of this research is that during the focus group interview one father participated in the study. This added to the value of this research, as most research tends to focus predominantly on the views of mothers, as opposed to that of fathers (Macfadyen et al. 2011).

5.8.2. Interviewer bias and reflexivity

It is imperative to bring up the issue of bias when it comes to qualitative research and the use of interviews, despite the benefits of collecting opinions from parents. Whilst the influences from the researcher and the participants are generally unintended, they need to be considered. Certain characteristics displayed by the researcher may have influenced the collection and interpretation of the results (Pezalla et al. 2012). As mentioned above, the results obtained assume that the parents providing their opinions were willing to share information with the researcher truthfully (Miles and Huberman 1994). Elliott et al. (2009) discuss how an interpretivist paradigm to research is subject to favouring and recalling information in a way that confirms one's established beliefs. However, whilst it is acknowledged that a researcher cannot completely abstract themselves from their own interpretations affecting the interpretation and analysis of results (Braun and Clarke 2006), certain measures were put in place to try to reduce this as much as possible. Firstly, some transcripts were randomly selected and coded by a professional colleague who did not know of the research. No conflicting results were reported. This ensured that the data was not coded only on the basis of the researcher's interests. Additionally, prior to analysis verbatim transcripts were sent to the participants to check the authenticity of the work.

5.8.3. Data collection tools

Additional limitations of the study relate to the data collection tools employed during this study. Focus groups and semi-structured interviews were used to collect data and therefore explore parent perceptions. The advantages of selecting these data collection tools have been discussed in Chapter 3. The focus groups were carried out first to provide a useful basis for individual

interviews later on (Morgan 1997). Additionally, they allowed for interaction between group members (Kitzinger 1994), which possibly led to an innovative understanding of the topics being discussed that would not have been collected from individual interviews alone (Millward 2012). Beginning with a focus group generated some initial themes, which were then delved in more detail through the one-to-one interviews (Mishler 1986). The individual interviews, carried out after, also allowed more time for the participants to express their opinions. In relation to the data analysis the data was analysed together. It was not the aim to compare the findings from both data collection tools, particularly due to time constraints, but rather to allow the researcher to collect in-depth information. Additionally, the recruitment rate was improved by providing parents with the option of attending either a focus group or a semi-structured interview. It also allowed parents to choose what type of environment they felt more comfortable in when discussing their issues, be it with other parents or alone.

Given the interviews were semi-structured in nature, with a set of questions used as a guideline, it is likely that the way the questions were put forward influenced the way the participants responded. However, using a semi-structured interview allowed the researcher to both collect a richness of data and also give a sense of direction (David and Sutton 2004). Additionally, the pilot interviews allowed the researcher to ensure that the questions were unambiguous. Lastly, the short interviews only offered the researcher a snapshot of an on-going long-term relationship that parents have with professionals around the use of VSSs. This may have resulted in some fallacies. However, the researcher and the participants had never worked together previously. Not knowing the researcher personally might have helped strengthen the accuracy of the data collected.

5.9. Conclusion

This chapter has discussed and interpreted the research findings. The research questions and the main findings were presented. It is recognised

that whilst the aims were achieved, there were limitations. The final chapter of this thesis presents a summary of the research, a personal reflection, and directions for future research and practice.

6.0. CONCLUSION

6.1. Overview

This chapter offers a summary of the main themes identified in this thesis. It describes the contributions made to research and goes on to discuss the implications for practice. This chapter offers suggestions for future research, which build on the findings of this thesis. Lastly, a reflection on the author's personal journey throughout this research study is presented.

6.2. Summary of thesis content

This thesis concerned the examination of parental perspectives concerning the support they received in relation to VSSs. It aimed to establish if parents participating in the study experienced the support to be of benefit and to examine the changes, if any, they perceived in their own understanding of VSSs as well as their children's skills. Key terms were defined at the start of the research. It was established that there is very little reported in research concerning parental perspectives of VSSs. The author's own experience also drove the need to explore this area in more detail. The literature review explored VSSs as a method for alleviating ASD characteristics. Evidence supporting the use of VSSs was presented. Additionally, the parent-professional partnership model of service delivery was explored to establish how successful partnership working occurs. Service provision around the implementation of VSSs was explored.

The research employed an interpretivist paradigm, a qualitative design, and a case study methodology. Strengths and weaknesses for selecting the above methodology were outlined. Data was collected using a focus group and a series of semi-structured, individual interviews. Ethical issues were also considered. A qualitative thematic analysis methodology was used to interpret the data obtained. Three major themes were identified from the data. These were: parent-professional partnership, perceived changes in abilities and skills, and experiences of using VSSs. Each theme was further

divided into a series of sub-themes. The sub-themes were: shared planning and decision-making, professionals' qualities, perceived changes in children's skills, perceived changes in parents' abilities and skills, enablers to using VSSs, and barriers to using VSSs. A discussion and interpretation of these themes and sub-themes was then provided. Strengths and limitations of the study were also discussed.

6.3. Contributions made to research

According to Petre and Rugg (2010, p. 18), at this level, a thesis should make "an original and significant contribution to knowledge". The reasons as to why this research study was undertaken were described in Chapter 1. In summary, professionals often recommend VSSs as an effective, evidence-based therapy tool for managing the communication and behaviour difficulties often associated with a diagnosis of ASD (Krantz and McClannahan 1998; Massey and Wheeler 2000). Despite quantitative evidence demonstrating improved benefits for children with an ASD (e.g. Ben Chaabane et al. 2009; Kashinath et al. 2006), parental views in relation to the implementation of VSSs is limited. It is thought that by collecting parental views, in relation to VSSs, a better understanding of issues will be obtained thus leading to improved guidelines for practice. Additionally, this may result in more effective evaluation of autism services. An autism-specific health service within the Republic of Ireland, using a collective empowerment model of service delivery, was therefore explored during this research study. This model of service delivery was examined, in relation to the use of VSSs, from the perspectives of parents.

By engaging the process of critical reflection on the service delivery model used within the researcher's workplace, a new understanding of the parent-professional partnership relationship, regarding the implementation of VSSs, was identified. Results revealed that for the most part parents were content with the support received from the professionals. Most professionals recommended the use of VSSs, as this was not always common knowledge.

Parents' reactions to the introduction of VSSs differed. Some were pleased with this decision from the start; others were more open to the idea once a clearer understanding of the therapy tools was obtained. Whilst most parents felt that the professionals demonstrated appropriate interpersonal skills, the lack of collaboration between health and education services was emphasised by some. Additionally, whilst the quality of information provided to parents was satisfactory, some parents commented on the lack of support offered. In terms of changes in parents' and children's skills following the support that they received, positive perceived changes were reported. Parents perceived that their children's skills improved following the use of VSSs. These findings resonate with quantitative literature. Parents' skills following the support and training were reported to have improved. Lastly, this research study established the benefits and challenges parents face when using VSSs. This study may therefore provide practical contributions to those working in partnership with parents of children with an ASD. Research regarding the perspectives of parents using VSSs is somewhat limited, and therefore the data collected should offer both parents and professionals with the issues that need to be taken into consideration when deciding on the appropriate therapy tool for the child in question. Implications for practice and suggestions for future research are further discussed below.

6.4. Implications for practice

Several recommendations are offered for reflection and potential areas for future research are suggested. Firstly, it is suggested that professionals, working with families of children with ASD, provide parents with an adequate amount of information in relation to VSSs. This will depend on the families' priorities. Providing families with information that suits their needs, and is delivered in a way that considers these needs, will allow parents to make an informed decision as to whether they would like to use VSSs with their children. It ought to be acknowledged that ultimately parents know what is best for their child and therefore they should be allowed to voice their opinions around the way services are delivered (Department of Health and

Children 2000). Therefore, regular discussions with parents are recommended as a way of meeting a family's needs, as opposed to providing a 'one-size fits all' model of service delivery. Regular, open discussions between parents and professionals are essential, as they will offer an opportunity for clarification regarding any issues. This way, parents and professionals are also able to understand each other's point of view.

It is suggested that service managers examine the way services are being provided. As suggested by Fullan and Miles (1992, p. 11), "reform must focus not just on structure, policy, and regulations but on deeper issues of the *culture* of the system". A parent's needs and resources may change over time (Carpenter 2000) and therefore it is "essential to ensure the parent partnership is aligned with those needs" (Magyar 2011, p. 207.) Time should therefore be spent getting to know parents and responding to their needs (Department for Education 2010). Whilst professionals perhaps acknowledge that a shortage of resources often determine how services are provided, it is recommended that they evaluate how services are being delivered to their service users. Professionals and parents need to be made aware that the definition of the word 'support' does not always imply direct contact with a family. Indeed, there appears to be disagreement amongst researchers on how the word 'support' should be defined (Frost and Dolan 2012; Katz and Pinkerton 2003). Additionally, literature appears to offer a distinction between 'family support' and 'parenting support'. Whilst this research study has concentrated on the relationship between parents and professionals, service providers need to acknowledge that the child, parent and families' needs should be considered as a whole (Paquette and Ryan 2011). Daly et al. (2015, p. 12) offer the following definitions of 'family support' and 'parenting support':

Family support is a set of (service and other) activities oriented to improving family functioning and grounding child-rearing and other

familial activities in a system of supportive relationships and resources (both formal and informal).

Parenting support is a set of (service and other) activities oriented to improving how parents approach and execute their role as parents and to increasing parents' child-rearing resources (including information, knowledge, skills and social support) and competencies.

From experience, professionals and parents are often preoccupied with the amount of direct contact spent with the child and their family. There appears to be this notion that direct contact constitutes 'real work' (Lawlor and Mattingly 1998) and is more effective. Indeed, this can be seen in the way care plans are often set up. It is frequently recommended that provision is described in detail and should typically be quantified, for example, in relation to the type, hours, and frequency of support (Department for Education and Department of Health 2015). It is therefore suggested that both service providers and service users have a shared understanding of the definition of the term 'support'. Parents and professionals should be made aware of the different models of service delivery that can be employed (McWilliam et al. 1995). An understanding, that support can be flexible, provided directly and/or indirectly is advocated.

It is the author's belief, writing as a researcher and practitioner, that parents and professionals often adopt the idea that more direct support equals more of the child's needs met. This appears to underpin and sustain practice in autism settings. It is recommended that service providers therefore rethink how we provide services to children with ASD by combining different service delivery models and pedagogies. Indeed, as recommended by ASHA (2018), combining different service delivery models allows for the child's needs to be met and offers opportunities to reflect on the effectiveness of intervention. Research concerning direct, one-to-one, Speech and Language intervention also supports this concept. Cirrin et al. (2010) and McGinty and Justice

(2006) have demonstrated that classroom-based services are shown to be more effective than traditional, pull-out therapy services. Parents and professionals need to be provided with information on the various models of service delivery and their effectiveness. Accepting a diagnosis can also form a huge part in determining how parents choose to engage with services (Cunningham and Davis 1985). Parents' previous experiences with services may have also had an impact on their abilities to form an effective partnership with professionals (Wall 2003). Practitioners therefore need to consider the relationships they form with parents and ensure that parents have the ultimate decision when choosing how they would like to work with professionals.

Parents also raised the issue of lack of collaboration between health and education services. Whilst there appears to be a shift towards multi-agency working in Ireland (e.g. Department for Education and Skills 2003), these findings are not new. Multi-agency working continues to be discussed in literature and government policy (e.g. Connelly 2013; Statham 2011). In Ireland, the importance of multi-agency working is stressed in government policy documents such as: *The National Children's Strategy* (Department of Health and Children 2000), *the 10-year Social Partnership Agreement Towards 2016* (Department of the Taoiseach 2006) and *The Agenda for Children's Services: A Policy Handbook* (Office of the Minister for Children 2007). What we do know is that it is effective, and therefore it is recommended that practitioners draw on this wealth of information. Professionals may need to be directed to this information to be able to reflect on their own practice. It needs to be acknowledged however that effective multi-agency working is not achieved easily and takes time. However, by considering the current literature it is a process that can be worked through. De-briefing sessions and team meetings are suggested for reflection of such issues. It is further suggested that a key worker system is introduced, as recommended by research carried out by Mullins (2008), and that families have one person and a single-access hub as a main point of contact. The

role of the key worker would be “for families to have one person who acts as their main point of contact, collaborates with professionals from their own and other services and ensures that access to and delivery of services from the different agencies and professionals is co-ordinated” (Sloper et al. 2006, p. 6).

In order to enhance parents’ partnership experience, it is recommended that the autism service in question implement strategies to encourage parental engagement and prevent possible barriers. Firstly, a method for trying to establish how much support parents require would be ideal. A flowchart may assist practitioners and managers in broadly determining whether parents are engaging with the service, or whether they want to engage further. For example, a flow chart that is used routinely might include questions such as: “are the parents engaging with the service?” YES/NO. “If they are engaging, have they got access to additional training opportunities?”, “If they are not engaging, can the service offer greater opportunities for parents to engage with professionals?”.

Furthermore, using Epstein’s (1995) definition of partnership as outlined in the literature review above (Chapter 2), it is recommended that a toolkit of creative ideas for engaging parents is created. Great strides towards improving the parent-partnership process can be accomplished through relatively inexpensive ways. Epstein’s (2001) framework of involvement can be applied to the current setting as a way of securing enhanced parental engagement. This can be seen in the tables overleaf:

TABLE 1.1.1 Epstein's Framework of Six Types of Involvement for Comprehensive Programs of Partnership and Sample Practices

Type 1 Parenting	Type 2 Communicating	Type 3 Volunteering	Type 4 Learning at Home	Type 5 Decision Making	Type 6 Collaborating With the Community
Help all families establish home environments to support children as students	Design effective forms of school-to-home and home-to-school communications about school programs and their children's progress	Recruit and organize parent help and support	Provide information and ideas to families about how to help students at home with homework and other curriculum-related activities, decisions, and planning	Include parents in school decisions, developing parent leaders and representatives	Identify and integrate resources and services from the community to strengthen school programs, family practices, and student learning and development
Sample Practices					
<p>Suggestions for home conditions that support learning at each grade level</p> <p>Workshops, videotapes, computerized phone messages on parenting for each age and grade level</p> <p>Parent education and other courses or training for parents (e.g., GED, college credit, family literacy)</p> <p>Family support programs to assist families with health, nutrition, and other services</p> <p>Home visits at transition points to preschool and to elementary, middle, and high school; neighborhood meetings to help families understand schools and to help schools understand families</p>	<p>Conferences with every parent at least once a year, with followups as needed</p> <p>Language translators assist families, as needed</p> <p>Weekly or monthly folders of student work sent home for review and comments</p> <p>Parent-student pickup of report cards, with conferences on improving grades</p> <p>Regular schedule of useful notices, memos, phone calls, newsletters, information on the school Web site, and other communications</p> <p>Clear information on choosing schools or courses, programs, and activities within schools</p> <p>Clear information on all school policies, programs, reforms, and transitions</p> <p>Information for parents on Internet safety</p>	<p>School and classroom volunteer program to help teachers, administrators, students, and other parents</p> <p>Parent room or family center for volunteer work, meetings, resources for families</p> <p>Annual postcard survey to identify all available talents, times, and locations of volunteers</p> <p>Class parent, telephone tree, or other structures to provide all families with needed information</p> <p>Parent patrols or other activities to aid safety and operation of school programs</p>	<p>Information for families on knowledge and skills required for students in all subjects at each grade</p> <p>Information on homework policies and how to monitor and discuss schoolwork at home</p> <p>Information on how to assist students to improve skills on various class and school assessments</p> <p>Regular schedule of homework that requires students to discuss and interact with families on what they are learning in class</p> <p>Calendars with activities for parents and students to do at home or in the community</p> <p>Family math, science, and reading activities at school</p> <p>Summer learning packets or activities</p> <p>Family participation in setting student goals each year and in planning for college or work</p>	<p>Active PTA/PTO or other parent organizations, advisory councils, or committees (e.g., curriculum, safety, personnel) for parent leadership and participation</p> <p>Independent advocacy groups to lobby and work for school reform and improvements</p> <p>District level councils and committees for family and community involvement</p> <p>Information on school or local elections for school representatives</p> <p>Networks to link all families with parent representatives</p>	<p>Information for students and families on community health, cultural, recreational, social support, and other programs or services</p> <p>Information on community activities that link to learning skills and talents, including summer programs for students</p> <p>Service integration through partnerships involving school, civic, counseling, cultural, health, recreation, and other agencies and organizations; and businesses</p> <p>Service to the community by students, families, and schools (e.g., recycling, art, music, drama, and other activities for seniors or others)</p> <p>Participation of alumni in school programs for students and as mentors for planning for college and work</p>

Table 6. Epstein's (2001, p.16) framework of six types of involvement.

TABLE 1.1.2 Challenges and Redefinitions for the Successful Design and Implementation of the Six Types of Involvement

Type 1 Parenting	Type 2 Communicating	Type 3 Volunteering	Type 4 Learning at Home	Type 5 Decision Making	Type 6 Collaborating With the Community
Challenges					
Provide information to all families who want it or who need it, not just to the few who can attend workshops or meetings at the school building	Review the readability, clarity, form, and frequency of all memos, notices, and other print and nonprint communications	Recruit volunteers widely so that all families know that their time and talents are welcome	Design and organize a regular schedule of interactive homework (e.g., weekly or bimonthly) that gives students responsibility for discussing important things they are learning and that helps families stay aware of the content of their children's classwork	Include parent leaders from all racial, ethnic, socioeconomic, and other groups in the school	Solve turf problems of responsibilities, funds, staff, and locations for collaborative activities
Enable families to share information about culture, background, and children's talents and needs	Consider parents who do not speak English well, do not read well, or need large type	Make flexible schedules for volunteers, assemblies, and events to enable employed parents to participate	Coordinate family-linked homework activities, if students have several teachers	Offer training to enable leaders to serve as representatives of other families, with input from and return of information to all parents	Inform families of community programs for students, such as mentoring, tutoring, and business partnerships
Make sure that all information for families is clear, usable, and linked to children's success in school	Review the quality of major communications (e.g., the schedule, content, and structure of conferences, newsletters, report cards, and others)	Organize volunteer work; provide training; match time and talent with school, teacher, and student needs; and recognize efforts so that participants are productive	Involve families with their children in all important curriculum-related decisions	Include students (along with parents) in decision making groups	Assure equity of opportunities for students and families to participate in community programs or to obtain services
	Establish clear two-way channels for communications from home to school and from school to home		Provide timely information to students and families on credits required for high school graduation, credits earned, and steps for planning postsecondary education		Match community contributions with school goals; integrate child and family services with education
Redefinitions					
"Workshop" to mean more than a meeting about a topic held at the school building at a particular time; "workshop" also may mean making information about a topic available in a variety of forms that can be viewed, heard, or read anywhere, anytime	"Communications about school programs and student progress" to mean: two-way, three-way, and many-way channels of communication that connect schools, families, students, and the community	"Volunteer" to mean anyone who supports school programs and students' activities in any way, at any place, and at any time—not just during the school day and at the school building—and those who are audiences for student events, sports, activities, and performances	"Homework" to mean not only work done alone, but also interactive activities shared with others at home or in the community, linking schoolwork to real life	"Decision making" to mean a process of partnership, of shared views and actions toward shared goals, not a power struggle between conflicting ideas	"Community" to mean not only the neighborhoods where students' homes and schools are located but also neighborhoods that influence student learning and development
			"Help" at home to mean encouraging, listening, reacting, praising, guiding, monitoring, and discussing—not "teaching" school subjects	"Parent leader" to mean a real representative, with opportunities and support to hear from and communicate with other families	"Community" rated not only by low or high social or economic qualities but also by strengths and talents to support students, families, and schools
					"Community" means all who are interested in and affected by the quality of education, not just families with children in the schools

Table 7. Challenges and redefinitions for the successful design and implementation of the six types of involvement (Epstein 2001, p. 17).

Adapting Epstein's (2001) grouping of types of parental involvement, the following strategies are recommended:

- Offering support to parents and teachers, in relation to VSSs, in both the home, school and clinic environment.
- Ensuring communication strategies are personalised to fit the needs of the family.

- Offering both formal and informal methods of communication e.g. direct parent training, information sheets, phone calls, information on notice boards, introducing social events such as 'get togethers' where parents can meet up and share ideas.
- Family training should be flexible in terms of how, where and when it is provided. Opportunities for fathers to attend training should be considered, including Saturday sessions for those families who work.
- Practice sessions for parents to practice making VSSs are recommended. Workshops with materials provided can be set up to encourage parents to practice their skills in the creation of VSSs.
- Parent-Professional partnership evaluations should not only be restricted to those working in the service. In addition, it is suggested that parents are also invited to attend meetings to discuss effective methods of the parent-professional partnership model of service delivery. Use of parental questionnaires to gather information is also advised.
- Consideration of the use of new technology for communication purposes. Resources should be available online to reach those who are unable or unwilling to engage directly with the professionals. Examples include: e-learning opportunities, a regularly updated website, podcasts, and online videos.

Lastly, parents should be informed of the benefits and challenges in relation to VSSs. A thorough assessment of both the family's needs, as well as the child's, will need to be carried out in order to determine the best VSSs for the child. The information presented in this thesis may allow professionals, such as Speech and Language Therapists and Teachers, to acquire a more comprehensive picture of parents' perceptions in relation to VSSs. With future research to support these findings, training to develop professional's interpersonal skills is warranted (Rodd 1998; Ebbeck and Waniganayake 2003). In summary, it is recommended that services and professionals working in the field of ASD allocate time to reflect on their parent-professional

partnership model of service delivery.

6.5. Dissemination of findings

Preliminary findings from this study have already been presented at an annual special needs and inclusion conference in Canterbury, U.K. (Mallia Borg 2017), as well as informally during work meetings. It is anticipated that the work will also be published in peer-reviewed journals and other national and international conferences. An information sheet with the findings will be sent out to both participants and professionals currently working in the examined service. Discussions with previous colleagues are also scheduled.

6.6. Suggestions for future research

As stated earlier this was a small study carried out in one setting. The aim was to give ‘voice’ to parents’ experiences of VSSs, rather than to generalise findings to a larger population. As a qualitative study, the study aimed to explore the meanings ascribed to the descriptions provided by parents within a specific setting, regarding the implementation of VSSs and their relationship with professionals. Further research might explore the nature of partnership working and VSSs across additional settings, using a larger sample. Additionally, future research may be warranted in the exploration of the perspectives of professionals working with parents in ASD services. Whilst this thesis has focused on the perceptions of parents of children with ASD, future research in terms of whether the results can be applied to a broader range of families with other special education needs is also suggested. Additionally, the results serve as a basis for more comprehensive discussions between parents and professionals within the service in question. Indeed, following this research study discussions in relation to the development of positive partnership working have already taken place amongst co-workers. This should enhance the way the organisation in question continues to provide services for parents of children with ASD. Examining behaviour change by comparing parents’ responses before and after the support is provided is also worthy of future research. Additionally,

whilst the effects of VSSs on children's behaviour and communication skills have been explored, further understanding of the benefits VSSs can have on feeding behaviours is necessary.

6.7. Reflection on personal learning

This doctoral journey can only be described as 'an adventure of a lifetime'. With its share of ups and downs, focusing on the light at the end of the tunnel has been the most helpful in ending this quest. Every setback in this journey, both personal and academic, was for the most part seen as a bump in the road. When issues were faced that threatened efforts, from the birth of a child to the end of a marriage, the sense of achievement after completing the thesis was what was held onto in order to stay focused and plough through. Not only has it allowed for personal growth, identifying what is and what is not important in life, but also development in terms of the writing process. This was evidenced through feedback and discussion with the thesis supervisor. The learning journey throughout the process has been invaluable. Learning how to become a better researcher, a more organised one, and most especially realising that 'failure' is just another word for 'growing'.

6.8. Conclusion

This study has examined the parental perspective and negotiation of responsibility with clinicians, as a way of meeting the needs of the clients effectively. In particular, the experiences of parents of children with a diagnosis of autism who used VSSs. Through the literature review concepts of parent-professional partnership, in reference to VSSs were explored. Definitions of key terms were provided. The parent-partnership model of service delivery within the study was explored. Research on the subject of changes in skills was also presented. The selection of an interpretivist approach, a qualitative design, and a case study methodology was justified. A discussion of the methods employed: focus group and semi-structured interviews followed. Ethical issues and data analysis procedures were also

discussed. Data was analysed thematically using Braun and Clarke's (2006) guidelines. Three major themes emerged from the data: Parent-professional partnership, perceived changes in abilities and skills, experiences of using visual support systems. Multiple sub-themes were also presented, including the qualities demonstrated by the professionals, and the enablers and barriers of using the therapy techniques. Explanations for the findings were offered and limitations of the study addressed. Implications for practice suggest the need for professionals to be aware of parents' needs. Time should be spent developing a relationship with parents to allow open communication to take place. Dissemination and areas for further research were also emphasised. It should be acknowledged that no two parents are the same, in terms of their strengths and needs. As the English idiom says, "a picture is worth a thousand words". However, in the words of John McCarthy (2007, cited in Wikipedia 2018, p. 1), a computer scientist, "as the Chinese say, 1001 words is worth more than a picture". Therefore, whilst there is evidence to suggest the effectiveness of VSSs, what one family may see as appropriate might not be the same for another. In the U.K., health secretary Andrew Lansley (2010) adopted the slogan "No decision about me without me" (cited in The Guardian 2010, p. 1). Whilst there appears to have been progress in the way parents and professionals share decisions, this research study demonstrates that there is some work to be done in making it an automatic part of excellent service delivery.

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APPENDICES

APPENDIX 1

DIAGNOSTIC CRITERIA FOR SOCIAL COMMUNICATION DISORDER AND AUTISM SPECTRUM DISORDER

Social (Pragmatic) Communication Disorder

Diagnostic Criteria

315.39 (F80.89)

- A. Persistent difficulties in the social use of verbal and nonverbal communication as manifested by all of the following:
1. Deficits in using communication for social purposes, such as greeting and sharing information, in a manner that is appropriate for the social context.
 2. Impairment of the ability to change communication to match context or the needs of the listener, such as speaking differently in a classroom than on a playground, talking differently to a child than to an adult, and avoiding use of overly formal language.
 3. Difficulties following rules for conversation and storytelling, such as taking turns in conversation, rephrasing when misunderstood, and knowing how to use verbal and nonverbal signals to regulate interaction.

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Neurodevelopmental Disorders

4. Difficulties understanding what is not explicitly stated (e.g., making inferences) and nonliteral or ambiguous meanings of language (e.g., idioms, humor, metaphors, multiple meanings that depend on the context for interpretation).
- B. The deficits result in functional limitations in effective communication, social participation, social relationships, academic achievement, or occupational performance, individually or in combination.
- C. The onset of the symptoms is in the early developmental period (but deficits may not become fully manifest until social communication demands exceed limited capacities).
- D. The symptoms are not attributable to another medical or neurological condition or to low abilities in the domains of word structure and grammar, and are not better explained by autism spectrum disorder, intellectual disability (intellectual developmental disorder), global developmental delay, or another mental disorder.
-

Autism Spectrum Disorder

Autism Spectrum Disorder

Diagnostic Criteria

299.00 (F84.0)

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).

- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).

- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor
(Coding note: Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder
(Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119–120, for definition) (Coding note: Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

TABLE 2 Severity levels for autism spectrum disorder

Severity level	Social communication	Restricted, repetitive behaviors
Level 3 "Requiring very substantial support"	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2 "Requiring substantial support"	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1 "Requiring support"	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V 2013) American Psychiatric Association 2013, pp. 47-48, 50-52.

APPENDIX 2

CARE PLAN DISCUSSION

Team:
Child: X

Date:
DOB:

Summary of discussion between parent and Early Intervention team:

- X is a 5 year old boy with a diagnosis of Autism Spectrum Disorder.
- X's mother is concerned that X needs to be verbally prompted to follow the morning routine at home.
- On meeting X, the Speech and Language Therapist is concerned that X is finding it hard to understand what is expected of him when verbal instructions are given.
- The parent and early intervention team met and chose the following annual goal as one of the priorities for the year.
- The goal read: "Using a visual schedule, X will independently complete 4 out of 8 morning routines at home on 3 consecutive days".
- The Speech and Language Therapist and parent agreed that X's mother will participate in a parent information session focusing on the use of visual schedules.
- The Team and parent agreed that they will continue to support X's mother to implement the schedule at home – through home visits, discussion, role modeling.

Goal	Action/Intervention	Who	Review Date
Using a visual schedule, X will independently complete 4 out of 8 morning routines at home on 3 consecutive days.	Family to participate in parent training. Team to support family to use visuals in the home environment through home visits, discussion and role modeling.	Team Family	XX/YY/ZZ

APPENDIX 3

ETHICAL APPROVAL: HEALTH SERVICE EXECUTIVE

<div data-bbox="507 304 837 479"></div>	<div data-bbox="900 304 1267 376">Children with an Autistic Spectrum Disorder</div> <div data-bbox="900 387 1267 528"></div>
---	--

Ms Rachel Bugeja Mallia
Kaiserstr. 44 a
63065 Offenbach
Germany

21st May 2013

Re: The effects on parents' understanding of and attitudes towards using visual support systems, following participation in an interactive and multimedia training programme for parents of young children with Autism.

Dear Rachel,

Thank you for applying to the research ethics committee on the 9th March 2013. In addition, thank you for sending on your amendments as requested by the committee. I am pleased to report that the study (including the amendments) has been granted approval by the Committee.

If during the course of the research project, any significant amendments or alterations to the proposed research are required, approval must again be sought from this committee.

Wishing you every success with the study,

Yours sincerely,

[Redacted Signature]

[Redacted Name]

Secretary of the [Redacted] Ethics Committee,

Ph: [Redacted] E mail: [Redacted]

Members present when decision was taken:

[Redacted]

Chair / Clinical Nurse Specialist [Redacted]
Occupational Therapist [Redacted]
Speech and Language Therapist [Redacted]
Senior Social Worker [Redacted]
Psychologist [Redacted]
Senior Registrar [Redacted]
Clinical Psychologist, [Redacted]

APPENDIX 4

ETHICAL APPROVAL FOLLOWING MINOR AMENDMENTS

	Services for Children with an Autistic Spectrum Disorder

Name: Rachel Mallia Borg

Date: 14/01/2014

Re: Visual Support Systems: A Qualitative Evaluation of the Support Provided to Parents of Children with Autism

Dear Ms Mallia Borg,

Thank you for applying to the [redacted] research ethics committee, which was discussed on 08/01/2014. In addition, thank you for sending on your amendments as requested by the committee. I am pleased to report that the study (including the amendments) has been granted approval by the Committee.

If during the course of the research project, any significant amendments or alterations to the proposed research are required, approval must again be sought from this committee.

Wishing you every success with the study,

Yours sincerely,


Secretary of the L [redacted] Ethics Committee,
Ph: 0 [redacted] Email: [redacted]

Members present when decision was taken:

Chair / Clinical Nurse Specialist L [redacted]
Occupational Therapist [redacted] Services
Speech and Language Therapist, [redacted] Services.
Senior Social Worker L [redacted]
Social Worker

APPENDIX 5

QUEEN MARGARET UNIVERSITY ETHICAL APPROVAL

QMU Ethical Approval - R Mallia

Clapson, Lucy

Thu 3/20/2014 12:31 PM

To: MALLIA, RACHEL <10007657@qmu.ac.uk>;

Cc: Research Ethics <ResearchEthics@qmu.ac.uk>;

Dear Rachel,

Confirmation of ethical approval

Thank you for submitting your application and confirmation of external ethical approval for consideration by the Research Ethics Panel.

Dr Jane McKenzie, Convener of the Panel, has reviewed your documentation and has confirmed that she is happy to take Convener's Action to grant full ethical approval for your research.

A standard condition of this ethical approval is that you are required to notify the Panel, in advance, of any significant proposed deviation from the original protocol. Reports to the Committee are also required once the research is underway if there are any unexpected results or events that raise questions about the safety of the research. You will find the appropriate form for this at the link below:

<http://www.qmu.ac.uk/quality/rs/default.htm#ethics>

We would like to wish you well with your project.

APPENDIX 6

CONSENT FORM

CONSENT FORM

(This form is to be completed by child's parent. The form will be kept confidential and will be destroyed after the research is completed to ensure anonymity)

Title of Project:

"Visual Support Systems: A Qualitative Evaluation of the Support Provided to Parents of Children with Autism".

Name of Researcher:

XXX, Speech and Language Therapist ([Phone number])

Please read the following statements carefully, and then tick, ✓ either YES or NO:

I have read the Information for Participants letter about this study being conducted by XXX at Queen Margaret University.

☐ YES ☐ NO

I have received enough information about this study.

☐ YES ☐ NO

I understand that I shall have further opportunity to ask questions and discuss matters with the researcher should I need to.

☐ YES ☐ NO

I understand that I am free to withdraw from this study: at any time, without giving reason and without affecting any services received currently or in the future from **** Services.

☐ YES ☐ NO

I understand that confidentiality would only be breached if information arose during the interview regarding risks requiring essential attention.

☐ YES ☐ NO

I agree to take part in this study.

☐ YES ☐ NO

I consent to audio taping of my responses during the interview.

☐ YES ☐ NO

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

☐ YES ☐ NO

I would like to receive a written summary of this research project.

☐ YES ☐ NO

Participant Signature:

Participant Name: (please print)

Date:

APPENDIX 7

TRANSCRIPT CHECK

LETTER ASKING PARTICIPANTS TO CHECK WRITTEN TRANSCRIPTS

[Address]

[DATE]

Dear _____,

I am pleased to enclose a draft of the transcript based on the interview which took place for the study: **“Visual Support Systems: A Qualitative Evaluation of the Support Provided to Parents of Children with Autism”**.

I would like to take this opportunity to thank you for your contribution. I have endeavored to represent all the views expressed and to avoid presenting the information in any way, which would allow respondents to be identified.

May I remind you that quotations used in the dissertation will be given anonymously. I will not be attaching the entire transcript; instead the dissertation will only contain essential information, such as relevant examples and/or quotes referred to. The bulk of the interview information will be presented in a concise form such as a table or summary. I would be happy to receive any comments or further contributions by the _____, at which time the study will be moving into the next phase where I will be analysing the data as discussed. Should you wish to make any changes please write to the above address. Alternatively, email me at [Email]

Yours sincerely,

XXX, B.Sc. (Hons.)

Senior Speech & Language Therapist

APPENDIX 8

DEBRIEFING CONTACT SHEET

QUEEN MARGARET UNIVERSITY EDINBURGH

Researcher's Contact Details:

Name:	XXX, Speech & Language Therapist
Address:	XXX
Telephone:	XXX
Email:	XXX

Current Service Provider Details:

Name of Service:	XXX
Address:	XXX
Telephone:	XXX
Contact Person:	XXX

Early Services Team:

Name:	XXX
Address:	XXX
Telephone:	XXX
Contact Person(s):	XXX

Samaritans Ireland:

Website:	www.dublinsamaritans.ie
Address:	112 Marlborough Street, Dublin 1
Telephone:	1850 60 90 90

Should you wish to make a comment, suggestion or complaint about the *Health Service Executive*, please email the details of your experience to yoursay@hse.ie or contact the HSE info line on 1850 24 1850.

APPENDIX 9

FOCUS GROUP SCHEDULE

Schedule

The purpose of the interview will be explained and the information in the focus group introduction letter reviewed (Appendix 5). The participants will be asked to sign a consent form (Appendix 8).

Welcome Participants

“Hello, my name is XXX Speech and Language Therapist. First of all I would like to thank you for agreeing to take part in this discussion. Can I firstly assure you that you will remain completely anonymous. Your name or any other identifying information will not be included in this project. Please do not give names of professionals you have worked with. If that’s okay with you, we may begin”.

Explain Purpose of Focus Group

“Since attending the service you have been provided with information and support around using and implementing visual support systems such as PECS, schedules etc. Various professionals have worked with you and your child. Today we will be looking at your opinions around the support received. Looking at how you feel about using and developing these therapy techniques. Also, looking at whether there were any changes in your children’s skills following support. My role will be to guide the discussion. Let us first look at some ground rules”.

GROUND RULES

1. YOU DO THE TALKING

It is important that everyone gets a chance to participate. I may call on you if I haven't heard from you in a while.

2. ONLY ONE PERSON TALKS AT A TIME

3. THERE ARE NO RIGHT OR WRONG ANSWERS

Every person's experiences and opinions are important. Feel free to speak up whether you agree or disagree. It is important to get a wide range of opinions.

4. WHAT IS SAID IN THIS ROOM STAYS HERE

5. TAPE RECORDING THE GROUP

I want to capture everything you have to say. I will not be identifying anyone by name in the final report. You will remain anonymous.

6. TURN OFF YOUR PHONES

If you cannot and you must respond, please do so as quietly as possible and rejoin as quickly as you can.

“Well, let's begin. We've placed name cards on the table in front of you to help us remember each other's names. Let's find out some more about each other by going around the table. Tell us your name and your child’s favourite thing to do”.

Questions

Engagement/Icebreaker question:

1. Could you describe what you understand by the word *visual support systems*?

Exploration Questions:***Deciding on Goals and the Support received***

2. Could you describe how you and the professionals came up with the goal to work on visual support systems?
3. How satisfied are you with this goal decision making process?
4. What can you say about the way professionals involved you in identifying visual support systems as a goal to work on?
5. What are the most important things the support around visual support systems has done for you?
6. How satisfied are you with the way the support around visual support systems was provided?

Changes in Children's skills

7. How has your child changed since receiving the support?
8. Have you noticed changes in your child's communication skills since receiving the support?
9. Have you noticed changes in your child's behaviour since receiving the support?

Changes in Parents' skills: Understanding and Ability to Use VSSs

10. What can you tell me about your ability to use visual supports following the support you received?
11. How do you feel about using visual support systems?
12. How much do you feel you know about visual support systems following the support received?
13. What do you think about the different types of visual support systems that are available?
14. What are your feelings towards using visual support systems with your child?
15. How do you feel about putting together your own visual supports e.g. a visual schedule following the support you received?
16. What can you tell me about the time needed to make up your own visual supports?
17. What can you tell me about the benefits of using visual support systems? Are there any negatives you would like to mention?
18. How satisfied are you with the way you use visual support systems?
19. How would you describe your ability to make up your own visual support systems?
20. Are there any visual support systems that are working well at the moment in your child's life?

Closure:

- "Of all the things we discussed, what to you is the most important?"
- Provide a brief summary and ask "Is this an adequate summary?"
- "Is there anything else you would like to add, anything about visual support systems or anything else we have talked about". **Any other comments?**

Probes:

- "Can you talk about that more?"
- "Help me understand what you mean"
- "Can you give an example?"
- "Please tell me (more) about that..."
- "Could you explain what you mean by..."
- "Can you tell me something else about..."
- "Would you explain further?"
- "Would you give an example?"
- "I don't understand."

Thank you for your time!

De-briefing

APPENDIX 10

SEMI-STRUCTURED INTERVIEW SCHEDULE

Semi-Structured Interview Schedule

The purpose of the interview will be explained and the information in the interview introduction letter reviewed (Appendix 5). The participant will be asked to sign a consent form (Appendix 8).

“First of all I would like to thank you for agreeing to take part in this interview. Can I firstly assure you that you will remain completely anonymous. Your name or any other identifying information will not be included in this project. Please do not give names of professionals you have worked with. If that’s okay with you, we may begin”.

Brief Introduction

“You may have heard of visual support systems or visual aids before. A variety of professionals may have provided you with support around understanding and using these systems e.g. visual schedules etc. Support may have been provided via discussions or written handouts etc”.

Introductory Question

1. Could you describe what you understand by the word *visual support systems*?

Probe: If they haven’t used them, why? If they have, what type and how is it going?

Understanding and Ability to Use VSSs

“You have spoken about.....I am going to ask you a few questions about your understanding of visual support systems and your abilities to use them. Please feel free to comment and add extra information should you wish to do so”.

1. What can you tell me about your ability to use visual supports following the support you received?
2. How do you feel about using visual support systems?
3. How much do you feel you know about visual support systems following the support received?
4. What do you think about the different types of visual support systems that are available?
5. What are your feelings towards using visual support systems with your child?
6. How do you feel about putting together your own visual supports e.g. a visual schedule following the support you received?
7. What can you tell me about the time needed to make up your own visual supports?

8. What can you tell me about the benefits of using visual support systems? Are there any negatives you would like to mention?
9. How satisfied are you with the way you use visual support systems?
10. How would you describe your ability to make up your own visual support systems?
11. Are there any visual support systems that are working well at the moment in your child's life?

Probe:

Can you give me an example of that?

What did you mean when you said...?

Deciding on Goals and the Support received

1. Could you describe how you and the professionals came up with the goal to work on visual support systems?
2. How satisfied are you with this goal decision making process?
3. What can you say about the way professionals involved you in identifying visual support systems as a goal to work on?
4. What are the most important things the support around visual support systems has done for you?
5. How satisfied are you with the way the support around visual support systems was provided?

Changes in Children's skills

6. How has your child changed since receiving the support?
7. Have you noticed changes in your child's communication skills since receiving the support?
8. Have you noticed changes in your child's behaviour since receiving the support?

Closure

"And finally, are there any visual support systems that are working well at the moment in your child's life? Please tell me what is important when supporting parents to use visual support systems. Is there anything else you would like to add, anything about visual support systems or anything else we have talked about".

Thank you for your time!

De-briefing

APPENDIX 11

INVITATION/INTRODUCTORY LETTER INVITATION TO PARTICIPATE IN THE RESEARCH

[Address]

[Date]

Re: Research Project Entitled “Visual Support Systems: A Qualitative Evaluation of the Support Provided to Parents of Children with Autism”.

Dear Parent(s)/Guardian(s),

My name is XXX, Senior Speech and Language Therapist working with the *YYY Early Services* team. I am currently completing the final year of a Professional Doctorate Degree (Health & Social Sciences) at *Queen Margaret University*, Scotland. As part of my degree I am required to complete a research project. I will be conducting this research under the supervision of the university.

The purpose of my study is to evaluate the effectiveness of the support you and your child received around **Visual Support Systems** e.g. PECS, Visual Schedules etc. Specifically, to evaluate whether you found the support to be beneficial. Also, whether you have noticed any changes in your child’s skills following the support. Therefore, I would like to invite you to take part in my dissertation project as a parent of a child with Autism Spectrum Disorder. Parents are invited to participate in **either** a **Group Interview** **or** an **Individual Interview**. These are discussed below.

A. Group Interview:

If you decide to take part in the group discussion, here are some details of the procedure involved:-

1. A group **discussion** with you and approximately 4 other parents would be carried out. It would be approximately 1 hour in length and would take place at a mutually convenient time in our XXX office on the _____. Light refreshments will be provided. During the group discussion, I will ask some questions about your experiences in relation to visual support systems to date. The questions will be 'open-ended'. These types of questions encourage people to talk about whatever is important to them. They will invite you to "tell your story" in your own words. For example, "How do you feel about using visual support systems?". You may decline to answer any of the questions if you so wish. You may opt out of the study at any stage, without giving a reason and without any negative consequences.
2. You are encouraged to keep confidential what you hear in the discussion.
3. With your permission, the discussion will be audio recorded to facilitate collection of information, and later transcribed in written format for analysis. Shortly after the discussion has been completed, I will send you a copy of the transcript to give you an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish.
4. All information you provide will be kept completely confidential. Audiotapes and written transcripts of audiotapes will be identified by code known only by the researcher. Only I will know your identity. No other **** Staff will be aware of your participation in this discussion. Confidentiality would only be breached if information arose during the discussion regarding risks requiring essential attention. The anonymous results may be published in a journal or presented at a conference. The information that you provide during the interview will be grouped with answers from other people so that you cannot be identified.
5. After gathering discussion/interview results, I will be writing up a thesis. This will use information provided by parents to describe their

views in general about visual support systems. There will be nothing in the thesis that indicates the identity of participating parents or the identity of the **** Service. No names or any other identifying information will appear. If parents' comments are quoted they will be given completely anonymously. Participants may request a summary of the project after its completion.

6. Audio data will be collected on a password protected recorder. Audio data will be immediately destroyed following transcription. Written data collected during this study will be retained for 5 years in a safe, locked cabinet in my work environment and then will be reliably destroyed. Only I will have access to the collected data. Access to computers will also be restricted to the researcher. The anonymous results may be published in a journal or presented at a conference.

B. Individual Interview:

If you decide to take part in the individual interview, here are some details of the procedure involved:-

1. An **interview** with you would be carried out by myself, XXX. It would be approximately 1 hour in length and would take place at a mutually agreed location and time e.g. in your house or the XXX clinic. In the interview, I will ask some questions about your experiences in relation to visual support systems to date. The questions will be 'open-ended'. These types of questions encourage people to talk about whatever is important to them. They will invite you to "tell your story" in your own words. For example, "How do you feel about using visual support systems?". You may decline to answer any of the interview questions if you so wish. You may opt out of the study at any stage, without giving a reason and without any negative consequences.
2. See points **3-6** above (Section A).

What will I gain?

This research will provide parents with an opportunity to voice their ideas and concerns.

What are the benefits of the study?

It is hoped that the research will increase professionals' understanding of parents' experiences following the support provided, and may go towards informing the practice of policy-makers and those who provide these services. XXX itself is not running this study. Therefore they will not hear back any specific information given by particular participants. However, I do hope to provide XXX with overall findings, and this, we hope, will help us to improve the way in which we deliver services.

What are the risks or inconveniences of the study?

To the best of my knowledge this study will have no more risk of harm than you would experience in everyday life; however, a possible inconvenience may be the time it takes to attend the interview (group or individual).

What are my rights and can I stop being in the study?

Of course, participation is completely voluntary. Participation will not affect or prejudice any services that your child receives currently or will receive in the future from **** Services. Services will not be curtailed if you choose not to participate. You may withdraw from this study at any time, without there being any negative consequences. You may decline to answer any of the interview questions if you so wish.

Confidentiality and Anonymity

In the written project, **** Services will not be named and your responses will be completely confidential and anonymous. Also we ask you not to mention any names of professionals so that your replies will be kept completely anonymous.

Who do I contact if I have questions about the study at any stage?

If you have any questions or concerns about this study, please telephone me, XXX at [Phone number], or e-mail: [Email]. Otherwise please feel free to contact my manager, Ms. XXX at [Phone number]. If during the interview you experience any questions or concerns, you are advised to contact me or a member of the team by phone [Phone number] for advice regarding any issues brought up by participating in this research. Should you wish to make a comment, suggestion or complaint about the [Health Board], please email the details of your experience to [Email] or contact the **** info line on [Phone number]. If you would like to contact an independent person, who knows about this project but is not involved in it, please contact Dr. XXX [Email/Phone].

What should I do if I wish to participate in this research?

Please take time to consider whether you want to take part in this research or not. Should you wish to take part in this study, please complete the attached **“expression of interest form”**. Please return it in the stamped addressed envelope by_____. I would like to assure you that this study has been reviewed and received ethics clearance through the **** Ethics Committee. However, the final decision about participation is yours. Please indicate whether you would like to attend the individual interview OR the group interview OR any.

If more people express interest in taking part than are needed for the study, the required number of participants will be chosen using sampling methods will be chosen randomly, using ‘lottery-type’ selection. If this type of selection process is needed I will get in touch with you to let you know if you have been selected or not. If you express interest in participating I will be in contact with you via the contact details you provide.

Thank you for considering participation in this study.

Yours Sincerely,

XXX, B.Sc. (Hons.), M.Ed.

Senior Speech & Language Therapist (Email XXX/Telephone XXX)



EXPRESSION OF INTEREST FORM

(This form is to be completed by child's parent(s). The form will be kept confidentially and will be destroyed after the research is completed to ensure anonymity)

Please express your interest in participating in the research by returning the attached form in the enclosed envelope by: DD/MM/YY

Participant Details:

I would be interested in collecting data from mothers, fathers or both. I would be grateful if you would fill out the section below:

Please tick ✓ below:

- I/We am/are the parent(s) of a child with Autism Spectrum Disorder who is currently linked in/was linked in with the **** Early Intervention Services team. ☐
- I/We have read the attached information sheet and I/We am/are interested in taking part in this study. ☐
- I/We understand that the researcher will contact me shortly, and that I/We can withdraw from the study at any time without prejudice. ☐
- I/We would like to participate in the **individual/group/any** (please delete as appropriate) interview.

Please fill in:

Name(s) & Surname: _____

Relation to child: _____

Address: _____

Telephone Number: Home: _____ Mobile: _____

Date: _____

Thank you very much for completing this form. Please return it to the researcher in the stamped addressed envelope. Please contact the researcher if you have any questions.

APPENDIX 12

REMINDER/THANK YOU LETTER

[Address]

[Date]

Re: Research Project Entitled “Visual Support Systems: A Qualitative Evaluation of the Support Provided to Parents of Children with Autism”.

Dear Parent(s)/Guardian(s),

My name is XXX, Speech and Language Therapist. As you may be aware, I am currently completing the final year of a Professional Doctorate Degree in at Queen Margaret University, Scotland.

A few weeks ago, I sent out a letter together with an “expression of interest” form aimed at exploring your views around visual support systems.

If you have filled out and returned this form I would like to take this opportunity to thank you very much. For those with a busy schedule who have not had time to fill it in but who would still like to do so, I am sending this letter as a reminder. Enclosed is another “expression of interest” form for your convenience. Should you still wish to participate in my research study, I look forward to receiving your form in the enclosed envelope by: DD/MM/YY.

If you have any questions about the nature of the study, please do not hesitate to telephone me, XXX at [Phone number], or contact me by e-mail: [Email].

I thank you in advance for your assistance.

Rachel Mallia Borg
Senior Speech & Language Therapist

APPENDIX 13

SELECTED/NON-SELECTED PARTICIPANT LETTER LETTER FOR PARTICIPANTS TO SAY YOU HAVE/YOU HAVE NOT BEEN SELECTED

[Address]

[Date]

Re: Research Project Entitled “Visual Support Systems: A Qualitative Evaluation of the Support Provided to Parents of Children with Autism”.

Dear Parent(s)/Guardian(s),

A few weeks ago, I sent out a letter asking you to take part in an interview process aimed at exploring the perspectives of parents of children with Autism Spectrum Disorder, particularly in relation to visual support systems. I would like to take this time to thank you for returning the ‘Expression of Interest Form’.

For Those Not Selected: Although I do believe that the information you would have provided would have contributed greatly to the research project, unfortunately, you have not been randomly selected to take part in this study. However, thank you once again for your interest which I very much appreciate.

For Those Selected: I am pleased to inform you that you have been selected to participate in the research group/individual (delete as appropriate) interview. As described in the information sheet that was sent out to you previously, your participation in the study will involve you answering a few questions. Every effort will be made to meet you at a mutually convenient time and location. I will therefore contact you by telephone shortly, to arrange a date and time, and give you further information. May I remind you that should you wish to opt out of this study, you may do so without there being any negative consequences. Again, I really appreciate your willingness to participate in this important research. I look forward to meeting you soon.

If you have any questions, please do not hesitate to telephone me, Rachel Mallia Borg at XXX, or contact me by e-mail: XXX.

Wishing you all the best.

Yours Sincerely,

Rachel Mallia Borg
Senior Speech & Language Therapist

APPENDIX 14

EXAMPLE OF TYPED TRANSCRIPT

Interview with: P1

P1. Parent 1.

Interview between Rachel Mallia Borg and Respondent P1

RMB: So just the first question is can you just tell me what you understand by the words visual support systems, or visual aids?

P1: Well for us ... John is a very visual based child. So it aids him with his understanding.

RMB: Very good yes.

P1: So ... for him to be able to see something, you can tell him verbally ... but if he can see it in front of him ... that em ... helps in his understanding, and gives him kind of ... it gives him space then to process ... at his own speed.

RMB: What's been said to him, yes.

P1: Do you know because sometimes verbally, that's kind of too quick. Do you know?

RMB: Exactly, yes.

P1: So if he has something visual to look at ... he's looking at that ... at his own pace ... he's processing it as his own pace. And it just seems to really work for him.

RMB: Yes. So it really helps with his understanding then, the visuals, yeah?

P1: It's understanding them ... there's no problem with his understanding, you know with his ... intellectual ability or anything.

RMB: Sure.

P1: But it's just ... he just needs that extra time.

RMB: To process.

P1: To process and I think that's mainly what it is for John.

RMB: Very good. Ok.

P1: Do you know?

RMB: Yeah, and so ... would you use pictures, or ...?

P1: Em ... pictures and words.

APPENDIX 15

CODING EXCERPTS

Participant 1: (P1)

Interviewer: RMB

(pages 1-4 from transcript)

RMB: So just the first question is can you just tell me what you understand by the words visual support systems, or visual aids?

P1: Well for us, John is a very visual based child. So it aids him with his understanding.

Visual child.
Visuals help understanding.

RMB: Very good yes.

P1: So, for him to be able to see something, you can tell him verbally, but if he can see it in front of him, that em, helps in his understanding, and gives him kind of, it gives him space then to process ... at his own speed.

Visuals allow child time to process information.

RMB: What's been said to him, yes.

P1: Do you know because sometimes verbally, that's kind of too quick. Do you know?

Verbal information is gone quickly

RMB: Exactly, yes.

P1: So if he has something visual to look at, he's looking at that, at his own pace, he's processing it as his own pace. And it just seems to really work for him.

Visuals work for the child

RMB: Yes. So it really helps with his understanding then, the visuals, yeah?

P1: It's understanding them, there's no problem with his understanding, you know with his ... intellectual ability or anything.

Can be used with children without intellectual disabilities.

RMB: Sure.

P1:	But it's just, he just needs that extra time.	Visuals allow child time to process information.
RMB:	To process.	
P1:	To process and I think that's mainly what it is for John.	
RMB:	Very good. Ok.	
P1:	Do you know?	
RMB:	Yeah, and so ... would you use pictures, or ...?	Pictures and words used as visuals.
P1:	Em, pictures and words.	
RMB:	Yes.	
P1:	But simple words. Pictures and simple words, yes.	
RMB:	Excellent, ok. So, em, could you just describe how you and the professionals decided to work on visuals? You don't need to mention any names, and just kind of how did you come up with the idea to decide?	
P1:	Ok, well it was initially from, em, he was attending his em, speech therapist for about, emmm, two and a half. Not with AppleTree ⁷ , he started Little Acorns.	Speech Therapist first identified use of pictures.
RMB:	Yeah. Yeah.	Parent not familiar with visuals prior to Speech Therapist mentioning them.
P1:	And it was then, just from the beginning, do you know, I wouldn't have known anything about just visual aids. Em, she would have started with the first and next, or now and next schedule. I'd never seen anything like that before.	
RMB:	Ok.	
P1:	Even doing a speech therapy was very simplified, em ... using pictures ... do you know, for em ... his and her, you know it	Speech and Language Therapist used pictures. First time parent saw them.

⁷ Pseudonyms have been used to protect confidentiality.

	was all very simplified, all very pictures, that was the very, that was the first time I had been introduced to it.	
RMB:	So the speech therapist used them herself?	
P1:	Yes.	
RMB:	And you were, sort of, that's how you got to know about them?	
P1:	Yes, that's how I was initially exposed to it, emmm ... because she, you know John wouldn't have been very cooperative now at a session starting off, at all.	Child was not cooperative without pictures.
RMB:	Yeah.	
P1:	Do you know he was very anxious, very nervous, he would sit on my lap.	Child was anxious prior to introduction of visuals in therapy sessions.
RMB:	Yeah.	
P1:	Do you know, she really had to draw him out, so when she used these, em, you know ... I suppose little small schedules within her sessions.	Parent saw speech therapist use visual schedules with her child.
RMB:	Yes.	
P1:	That put him at ease a bit, do you know, and eventually, and then he did get to know her then over time. But definitely when he knew what was going to happen ... and em, she would explain to him verbally what was happening but she would always have, she would always have a little picture schedule that he knew what was going to happen in the session. So if he knew what was going to happen, if he knew what like his expectations were, he knew kind of there was a beginning, middle and an end, do you know, he could understand that bit, so that helped, that was my first introduction into it. And then he ... got a tutor from the home tuition scheme. Luckily enough. And then she was very	Visual schedules put child at ease during therapy sessions. Explaining to the child what was happening first and next, using both visual and verbal information, helped child cooperate. Home tutor also used visuals with child at home. Home tutor introduced social stories in the home environment.

experienced in visuals as well. So ... emm, she emmm, which I can show you later, she em, was very experienced with the social stories. So say for example, one big example would be getting his hair cut. Do you know, absolutely terrified of that, and we worked really hard on that but with the help of the social story. And it was really the social story, ... again, because he knew what his expectations were. He still doesn't like getting his hair cut, but he knows what is happening, and even now like, we always, you know, I'd have the whole folder of stories there, anytime we go to do any of these situations, we take out the story, read through it, go through it. So it started initially with speech therapists, and then with the help of his home tutor, and then when he moved into AppleTree then, they definitely you know, but I mean that was kind of nearly second nature to us, you know you'd go in, you'd see the schedules everywhere. Any session you do, OT, speech, the Lego therapy, there's always a schedule up. And ... you know, the children, you can see they're drawn to it straight away. Do you know?

RMB: It's just so effective, yeah.

P1: It's so effective, again ... beginning, middle and end. They mightn't even be enjoying some of the sessions too much but they know, do you know, there's an end point to it. Another story I had was for when em, John was, em, starting pre-school. That was very hard now, to get him to go, you know to ... to draw him away from me, to go ... well he was going with his tutor, it wasn't that he was going on his own. But she said it was important, say for example at the end of the story that there was a picture of me and him having lunch at the end of the story. So he knew that he was coming home to me. Do you know, so it's definitely all the sequencing of the story, or the schedule. Em, so that's where we started off initially. Speech

Social stories helped with skills such as hair cutting.

Social stories helped child understand what was expected of him, despite not necessarily enjoying the activity.

Parent uses social stories at home after she saw that they work.

School later introduced visuals.

Child was familiar to visuals prior to attending school.

Parent can see use of visuals in school environment.

Parent can see that children enjoy these visuals.

Visuals help children understand there is an end point to an activity.

Visuals helped child transition into a new school environment.

Home tutor made up story for child to understand new transition.

	Therapist, then with his tutor, and then followed on into AppleTree.	
RMB:	And ... so the professionals kind of told you about the visuals.	
P1:	Yes.	
RMB:	And then did you begin to use them yourself at home or ...?	
P1:	Em, yeah, we used them at home, again I'll show you around the house, all the different schedules that we have set up, but definitely when it came to the toilet training, washing hands, going to the toilet. It was em, a daily schedule that he does with his tutor every day. He has, em ... to encourage him to talk. Now John is verbal, but that doesn't mean he's good at speaking, do you know, or very good at expressing himself. He's not very good at starting a conversation. He can be a bit em ... well, I don't know, maybe a bit lazy, but you know, that he still points instead of asks, you know? So he has a board of what I did today. Again, it's a visual board, again it's just encouraging him to talk about his day, without putting pressure on him. He doesn't always use it, but then every now and then, you know, some days he'll just go up and he'll pick it up and Mammy, I'll show you what I did in school today.	<p>Parent used visuals at home following introduction of them by professionals.</p> <p>Visuals encourage the child to talk without putting pressure on the child.</p> <p>Visuals encourage the child to participate in daily activities such as going to the toilet.</p> <p>Despite the child being verbal, his communication skills are not effective.</p> <p>Child doesn't always use visuals but knows they are there if he needs them.</p>
RMB:	Very good, yeah.	
P1:	And then I say, any new activity, em ... do you know, even ... when he was going on his school trip last year. Like, that was a huge thing. So any new activity, we would do a social story, and then we also just have the regular if you like, visual schedules for the house that we use. Yeah.	Social stories are used for any new activity.
RMB:	So how satisfied were you with the decision to work on visuals then?	

P1:	Oh, well not realised ... I didn't realise obviously in the beginning how effective they would be. But em ... do you know, when I saw them working like, absolutely definitely.	At first parent did not realise how effective visuals might be.
RMB:	Very good.	Once she saw them working, she was satisfied with the decision to use them.
P1:	Yeah.	
RMB:	Ok, and then the next question is, what was the most helpful about the support you received around visuals?	
P1:	Em ... just, just learning about them, full stop. Do you know, and just ... helping me get inside the mind of a child with ASD, do you know, that they just, they just don't process things in the same way as us, to know that they need a bit of extra time to process things, and the visual schedule helps them with that. And also just know what their expectations are. Because it was just, just learning that, do you know, to try and understand how John thinks. Do you know, like, say when he was getting his hair cut at first like before I had any help, I used to use the method of, that I won't tell him until the last minute. So therefore he hasn't got time to get worried about it and kick off and say he's not going like, so you'd be in the car and say, oh there's the hair shop, let's go in. But of course that was totally, the total wrong thing to do, do you know, because obviously the child got the fright of his life, he'd no time to process, prepare himself in his head, and he still screamed. So that was the total wrong approach. So then rewind back and ... you know, do the preparation, he knows what's happening. He still gets nervous and he still doesn't like it, but because he knows ..., so there's a, there's a brilliant example of, do you know, how you can think, by not telling a child so that they don't get upset, but rewind it back and know they actually do need to know. And for John, it's seeing it visually, not hearing it verbally. And even	<p>It was helpful to learn about visuals.</p> <p>It was helpful to understand how the mind of a child with ASD works. That they may need extra processing time.</p> <p>It was helpful to learn that visuals help children with their processing skills.</p> <p>Visuals help children understand what their expectations are.</p> <p>Visuals help a child 'prepare' for unpleasant experiences.</p> <p>Parent found it helpful to learn that children with ASD require preparation before unpleasant or unexpected events.</p> <p>Seeing things visually helps the child understand better than hearing it.</p> <p>Child happy to look at social stories on his own in his own time.</p>

	then, he would sometimes just even on his own, he would sit down and flick through his little story.	
RMB:	Ok. So again, just in terms of the support that you received. Were you satisfied overall with, with the information you have been given?	Parent satisfied with the information given.
P1:	Yes. Yes.	
RMB:	Tell me a bit about the information so far.	
P1:	The information, I suppose, I have to say most of the information and support I would have got visually, would be from his tutor ..., em, as I say because she is so experienced and just knew ... so well, how to do the stories, how to just keep it plain, simple. Now, I also did, in AppleTree, now they did also do a course on social stories.	Home tutor provided most of the information to parent around visuals. Home tutor was very experienced in the area of visuals. Parent training was helpful.
RMB:	Ok.	

Participant 2: (P2)
Interviewer: RMB

(pages 5-8 from transcript)

(talking about use of PECS)

P2:	And then the ... if you like, the support and the homework and the tuition that we got from the school, ... the behaviour, the behavioural psychologist is that, that's who ran the school, in Pear Tree ⁸ , they were fantastic. And every time they moved on a step using PECS, or if they were introducing the schedule, or the first then card, we got written information on the foundation of it, why it's effective, ... pitfalls, you know things that can happen, and then how to do it, and then, the	School supported the parent to use PECS at home. Homework was helpful. School staff were fantastic. Written information was provided to parent on how to use visuals at home, why they are important, and how to deal with
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⁸ Pseudonyms have been used to protect confidentiality.

typical problems you would run into and how to battle with that, because it's great when you're doing something until you run into a problem and then ... because Lucy started scrolling, so she'd run through several actions ... for something, and ... you know she might say I want ... whatever it was, I want let's say crisps. And, we were doing our, saying well that's not available but you can have, and we would give her a choice board. And it was all getting lost in translation and she would start scrolling through things that she thought she had to do.

RMB: Oh yeah, like manual signs?

P2: Yeah, and things like, they might be teaching her ... because it was the ABA, do this, do this, now do this and then she would get a reward, whether it was a toy or whatever sort of tangible, or edible or what not, in order to, you know to go through that. And then [laugh] she started to associated, because then she fell in love with crisps, and biscuits and all that, and she started to associate those activities that she was asked, those skills that they were trying to teach her, with the particular reward, so then she'd come and she'd get a thought, oh I want this ... and, we might not have them, or it's inappropriate for her to have them, because she hasn't eaten anything else ... [laugh] and she would, her mind would start racing on all the things she had been learned, you know taught to do. And she'd start ... she was doing all of this, and I was, it was like traffic control in front of you, and then I would be, I had no idea what's going on here, I know she's doing a lot of actions that she's obviously been taught, and sometimes she'd grab a colouring book and start ... and then show it to me like this, or ... and then, I'd say use your PECS pet, and she'd go back and I'd say well they're not available you can have ... and, we were lost. But then called the school or the next day send in a note,

common problems when using PECS.

Written information was provided every time child reached a goal.

When one is using visuals at home, difficulties may be encountered.

At times, child was using different 'rules' when using PECS – too many systems being introduced at once?
- PECS has rules. What happens when they are not followed?

School, through open communication with the parent, was able to provide solutions to problems being encountered in the home environment with visuals.

and they'd say, they'd identify it and they'd say or that's scrolling, because she's made a deep association with this, so when scrolling happens this is what you need to do. And we had to set up several situations where she would scroll, because it required two people then to either backwards step, or four chain correction, or, you know different things like that, but in that sense we found ... the schools and the supports great.

PECS requires two people.

RMB: And were there any negatives of the support?

P2: To be honest with you, ... the negatives so far have been, Lucy since has changed school and has gone to, let's say a State ASD pre-school class, and ... they are not so much in favour of ... PECS, or the use of, they will use a visual schedule, em ... and they do do it in school, but ... they are not so much into the individuals, em ... I mean that's her form of communication. And, they only use it at snack time, which we find is a huge problem here now because we find her trying to communicate in other ways, as in using her hand as a tool, or dragging us to wherever she wants and starting, you know, almost as if to say read my mind, this is what I need or I want, or I want to do. And we have to keep bringing her back to her communications system and, she uses it, she will and wants to use it for food items, but not necessarily, and we spent a long time developing that. So, we find that a negative. Also, and this, I suppose this is a huge criticism ... it took us a year to get INTO Olive Grove services and then when we did get in, I thought brilliant we've access to, you know, the different therapies, and I explained you know this is where Lucy is with her PECS and everything else, and we were hoping for support on, right, let's take a full examination of where we're at, and where she's at, and let's see how we can move on to the next step, particularly when it's not

New school is not so much in favour of using PECS. Only use it at snack time.

School not on board with parents' goals.

Parent has noticed regression at home because of school not using PECS frequently.

Waiting time for specialist support was long. Delayed services.

Parent explained to specialist services the goals they had been working on in terms of PECS.

Parent expecting assessment of child's skills to develop new goals in terms of PECS. Little service provided.

Parent disappointed with lack of

coming from school, and to be honest, we've had nothing apart from an invite to go to a social stories group. And with the no promise of, either. And ... Lucy is now starting to use language and ... myself and my husband, I mean we're not professionals, or ... in this area but we do feel ... there should be a language, or a functional communication programme in place, coming from our SLT, from Olive Grove, and we should have goals and objectives on a monthly or whatever she feels basis to do that. Or, at the very, because, you know, our speech and language therapist has been here, and ... she feels it's ok for Lucy to communicate in many different ways. Em ... and yes, if we feel strongly enough about it then to bring her back to her PECS. The problem is, is that that, as far as the research I have read, for children and adults with autism is, it's ... you use one mode of communication. Obviously they will, you know there are many others like gestures, or signs, or what have you, but we can't simultaneously teach her all of them, and it's not appropriate to have a PECS system where she uses visual aids, and especially link that with the choice board and first then, and schedules, and then have certain signs for certain words. So, you know, you have a couple of signs for particular things, and then you've a couple of pictures for other things. It's too universal, it's too ...

RMB: Sort of needs one system to be learned well?

P2: I think so, yes.

RMB: Yes.

P2: You know, we don't ask people to learn six or seven different languages, we ask them to learn one. And, I do remember one particular occasion, I suppose we had a session here, where ... I had become extremely frustrated that nobody was

support around use of PECS. Only received one invite for a social story presentation.

Despite not being professionals, parents felt a communication programme, with regular reviews, for the child should have been developed by the specialist support services.

Speech and Language Therapist provided home visit explaining how it was ok for the child to use different methods of communication. However, parents felt that one mode of communication was better for their child and that PECS should have been given priority.

Parents felt that one communication system was more appropriate. Professional not on board with parents' goals.

Parent frustrated that no one was on board with her goals and how important she felt it was for her child.

seeing how important this was, and that, that I was still trying to understand what was the service I was supposed to be getting, or Lucy was supposed to be getting, and I still really don't know to be honest, and we're with Olive Grove since September. So in that sense it's kind of, it's where I would have expected strong support and strong push, that's fallen through. Because I had really hoped that if we had got that, then they could have then pushed back on the school a little bit along with myself to say look, you know. So in that sense that has been our only negative experience. Otherwise we're a house very much into you know...

RMB: I guess, you know, with visuals as you were saying, you know, you really do need to ..., to have the support from the people around you.

P2: Because we get very lost, and we don't know, and now that she's starting to use the language, we feel this is PERFECT, it's at the beginning, it's the perfect opportunity to expand on this, but really in all honesty the impression I'm getting is, if the child doesn't have language, adequate language and is using that language enough, then there really is nothing for a speech and language therapist to work on. And my understanding was that's not what SLT provides, as a therapy for children with autism. We're not talking about, not being able to pronounce correctly, or, do you know what I'm talking about, the physical and difficulties with speech and language, and I just feel that's our negative there. Because I'm sure there's loads more we could be taught to help Lucy. And XX as well come and go. Now we haven't started PECS with him, but he is familiar in the sense that he's always been around it. He's very fond of the Velcro and we're, you know, he's desperate for eating them. But [laughs] I know, he's desperate for eating them, but

Parent was not made clear about the type of support she and her child would receive.

Strong support was not available.

Parent did not feel supported by specialist services to 'push' the school to use visuals.

Parents don't always know the best way forward and need the support from the professionals.

Parent felt that the attitude of the speech and language therapist was that if a child has no language then there is not much to be done.

Parent felt more support around communication skills was required. Both in terms of support to parents and to child.

Sibling also interested in visuals.

Fine motor skills affect handling of pictures.

we're teaching him just at the moment because his fine motor isn't great, he's only two. But to take them off the strip and put them back on, and he does see Lucy using, and if we have them on it we will, oh it's bath time, we'll show him the picture, bath time, and then we're going to, and we'll just give him a quick like a flash card. But we're just kind of introducing him to the whole. These are not for eating, they're for looking at [laughs].

RMB: So to aid his comprehension kind of, understanding.

P2: Yes. We just kind of throw the picture with the word and give it ... time, but then he wants the picture for the plastic, and to eat, so we're, but we're hoping later this year to start him, but we know we're going to have to do it ourselves, and that means I need dad to be here because you need two. You definitely need two.

RMB: That's kind of like a negative of the PECS in itself.

P2: Well it is, that the process, it ... requires two. And it takes a lot of planning to get started, because you can't do it one day and then not do it the next day. You know. And then plus, there, they are not great eaters, they have very big food problems. And em ... you know you start, the PECS starts with the things that the child most desires.

RMB: Exactly, yes.

P2: And it was great with Lucy because she'd never had anything sweet, except naturally sweet, until she was two and a half. But Robert just, oh my god, loves chocolate and biscuits and, he's only two.

RMB: Yeah, and then he has to eat all these small biscuits.

Parent uses visuals at home with siblings.

You need two people to teach visuals at home.

Using visuals takes a lot of planning.
Visuals have to be used consistently making it harder at times.

The disadvantage of PECS is that it uses food as a motivator, and when the child is not motivated by food this can cause issues.

P2: This is it.

RMB: Just to get him to request so often yeah.

P2: Exactly, and to do that, and then, you know when they ask you can't say, oh no, no, you can't have that. So because I've got the other food issue side of it, we really have a lot of planning to do and we're kind of dreading Robert a little bit. [Laughs]

You must give the child a treat if they ask for it under PECS rules.

RMB: It is so much planning.

P2: Yeah, Lucy loved things she could throw up in the air and watch the way they would fall and, and em ... play-dough and toys and things like that, whereas Robert just kind of, pff, pff, pff, pff, we know that his strongest motivator would be a biscuit, or a bar, a whole bar of chocolate at this stage [laughs]. So, that would be a negative of the PECS. But we've always found a way around it, but, particularly with Lucy. So in that sense, I suppose it's a negative of the system, but ... what you get once you get past it far outweighs the difficulty, and there's difficulties with everything. And I know my children wouldn't be, Lucy has some signs, but she just wouldn't take, she's a visual child, you know.

If sweets are a strong motivator this can sometimes be an issue. However, there are ways of dealing with it which outweighs this difficulty.

RMB: She likes pictures.

Child is visual.

P2: Yeah, and they study the detail in books and they love the DVDs, have to be on all the time and we try and turn them down lower and lower until we can eventually turn them off and then expand that time. But really the children don't do much unless that is going.

Child studies detail in books and likes DVDs.

RMB: TV

P2: Oh yeah, yeah, and then can tell, like, Lucy will leave the room two or three minutes before a particular clip let's say is going to come on the DVD, or up on the, whatever

DVD they are watching. And they have, oh nearly over 100 of them. But ... because she knows Robert is going to get upset or doesn't like, and you know this, this will make you laugh, there's two years and three weeks between them, it's the same DVD's that Lucy had that Robert has, em ..., they're not children that like things to be fast forwarded or re-winded, some children love that, but the exact same spots of the exact same DVDs that really caused Lucy massive distress, we're now starting to see it in Robert. And it's like, oh my god, how, what, ..., this can't be right, and it's very single, and it's not because she's getting upset, because we know she's, he was getting upset at balls or something, and then it struck me, oh my god Lucy used to get upset about that. And then we've to de-sensitise for all the little things. But now she starts to leave the room when she knows he, there's a piece coming up that he's going to ..., you know. Ridiculous.

RMB: So the crying upsets her.

P2: Yeah.

RMB: Ok, so the next set of questions are around sort of your understanding and ability to use visuals. So, just tell me a bit more about your ability to use visuals. What can you tell me about that?

P2: Well, we've trained in the PECS to do it. I'm great at laminating now, when they don't break it [laughs] or things like that. Em ... we simplify our language. I suppose, ... we use a lot of visuals ... with less language, if you know what I'm saying, and then we build the language once we know they've locked in the image for. In that sense.

Parent paid for PECS training.

Parent good at using laminator following practice.

Laminator can break.

Parent uses visuals and simple language following training.

Participant 3: (P3)
Interviewer: RMB

(pages 9-12 from transcript)

RMB: So you use them to help his understanding then as to what he's eating, yeah, yeah?

P3: Yes. Yeah. He occasionally requests this little one. iPad sometimes. Em ... loves the TV ones.

Enjoys requesting ipad and tv programmes with use of pictures

RMB: Oh very good.

P3: Which was actually, was eh ... we introduced with Clara a little while ago, because he, I suppose when he was younger he used to go through, you know, he'd be going through a phase, you know where he would take you by the hand and led you to the TV and then he kind of stopped doing it for ... for quite a while. And then probably about two or three months ago, he started doing it again. So, I suppose it was more, I was just kind of thinking, ok, right that's great, he's letting us know that he wants the TV. But I was thinking realistically it must be incredibly frustrating when you turn on the TV, it's like well what do you want? You know, so I was kind of saying oh, well hang on maybe if we do some, some pictures, and literally like the first day we put them in it was just like, [laughs], yeah, it was hilarious. Yeah, so he really, really took to it. So that's predominantly what he would use it for. Now obviously we're hoping as time goes on that we can kind of ...

SLT and mum worked on goal together.

Mum identified that using pictures for TV time might help child express his needs.

Child responded well to use of pictures.

RMB: Expand.

P3: Expand on that. But you know, it's just great that he's, you know he has some method of communicating.

Pictures provided the child with a method of communication.

RMB: Yeah, I notice that the pictures would be

quite large compared to some, is that for a particular reason, or?

P3: Yes, yeah. I think it's just for him to understand them better. I think, because I think at this stage it needs to be kind of the, sort of more the photograph if you know what I mean, for him to ... try and understand.

Photographs are easier understood currently.

RMB: Do you find he understands the photographs?

P3: Yes, I think he does, yeah. I think he does.

RMB: And where would you get your pictures from, or who makes them?

P3: Well Clara did most of these for me actually. Milk and stuff, I think the milk ones I did myself. I think the fig rolls, but I think Clara did a fair, good amount of them for me yeah.

SLT made most of the pictures for the client. Mum made some too.

RMB: Very good.

P3: Yeah, she did, which is great.

It was great that SLT made the pictures for mum.

RMB: Do you ... eh what about the other types of pictures that you have. Like these are line drawings ...

P3: Yeah, well I suppose that's probably the only one I have, line, most other ones I have, visuals are more ... em ... like the photographs and stuff.

RMB: Yeah.

P3: Say I have like [Velcro ripping sound] the playground, and ... you know, different family members and stuff and whatever, so, like we just took, you know.

RMB: Ok, so you took photographs and laminated them.

P3: Yeah, yeah.

RMB:	Oh very good.	
P3:	And then Clara did these ones for me as well.	
RMB:	Oh yeah, so these are his different OT activities?	
P3:	Yeah, and obviously then just saying you know, it's bath time, or ... or whatever, you know.	Photographs are used to help the child understand what's first and next during his daily routine.
RMB:	Oh very good, yeah.	
P3:	So ...	
RMB:	And how did you discover that he sort of understands photographs better, like how did you come up with that?	
P3:	Well, I suppose it was really just, I think talking with Clara. Because originally we looked at the pictures, and she was saying just that they tend to be kind of the easiest to understand, you know?	Talking with SLT helped mum establish goals for child.
RMB:	Yeah, because they can be quite abstract, the line drawings.	Line drawings can be harder to understand.
P3:	Yeah, yeah, so that's why we went for the photographs.	
RMB:	And have you ever made any visuals yourself?	
P3:	Yeah, well I say, the milk ones and stuff I've done myself.	Mum has made her own pictures.
RMB:	Oh very good.	
P3:	I did the fig rolls as well, I think. I think the other ones are from Clara, but yeah, I've done some myself. Actually my sister-in-law was trying to show me the other day, but I haven't got it quite figured out, I haven't got PowerPoint on my eh, because she was going to show me a thing for sizing them, or whatever. So I need to do that, because obviously that's	Mum is working on using technology to size pictures. Mum uses a laminator.

	why some of them are slightly different sizes. But yeah apart from that you know, and I have a laminator and stuff. So you know.	
RMB:	And where would you get your pictures from. Like the milk one? Where did you get that one?	
P3:	I think just Google images, which tends to have pretty much everything on it. [Laughs] You know, more or less.	Uses Google images.
RMB:	Yeah, and would you feel confident looking them up, looking the pictures up and using the programmes.	
P3:	Oh yeah, yeah.	Feels confident looking up pictures.
RMB:	You almost have to be quite a, a bit of a high tech person really don't you?	
P3:	God now I certainly wouldn't describe myself as that, [laughs] but as I say I do need to figure out, em ... in terms of sizing them, because I know you can get things like boardmaker® and stuff, but from what I can gather they are pretty expensive.	Some programmes for making pictures can be expensive.
RMB:	Yes. Yeah, BoardMaker®, we have BoardMaker® in the office so ...	
P3:	Yes, yes, I'm sure that's obviously with Clara. But actually my sister-in-law is actually a speech and language therapist.	
RMB:	Oh very good.	
P3:	But she lives in England. So, she was saying there's something on PowerPoint where you can sort of put in and size them or whatever, and she said it's very, so as I say, she was trying to talk me through it the other night, on Facetime, [laughs] but I don't have PowerPoint so I need to get it on the PC and then I'll be able to sort of have the more kind of consistent type signs or whatever, you	Mum obtained advice from others to show her how to use some technology on the computer for making pictures.

know.

RMB: It makes it looks a bit nicer, I guess.

P3: Yes, exactly.

RMB: Ok, and so how do you feel about putting together, I mean you mentioned that you are pretty confident, but, is there anything else you'd like to add as to how you feel about putting your own visuals together?

P3: No, as I say the only thing really is just kind of getting to do the sizing, but apart from that like, I'm quite ...

RMB: And laminating, and Velcro?

P3: Yeah, no, absolutely, well as I say, my sister in law whose a speech and language therapist bought me the laminator. It's probably about a year and a half ago now and she was going, you will need this. And she was very right, because you know yourself, anything you're using it just gets completely wrecked if you, if you don't laminate it, so. So yeah. She obviously knows her stuff, so she eh ... got that for me. Em ... so as I say mostly yeah, google images, have the laminator, emm ... Velcro and stuff, I just ordered more of that on Amazon. And I just get big rolls of it, you know, it's fairly inexpensive and stuff or whatever, so it's ok.

RMB: Yeah, and tell me a bit about the time it takes to make visuals.

P3: Em ... well yeah, it can, can be a little bit time consuming, but I suppose I'm in the position at the moment that obviously, ... Liam and my daughter Rebecca as well, obviously they are in school in the morning, and I'm not working so ... you know, I have the time to ... to do it. Obviously maybe if you were working and stuff, you might be slightly more under pressure and that because, you know

Getting pictures all the same size can be tricky.

Laminating the pictures helps protect them.

Velcro is fairly inexpensive. Buy in bulk.

Making visuals can be a little time consuming. Mum has time to do up the pictures as not currently working.

Making pictures is the kind of thing you need to do alone.

yourself, it's the kind of thing you need to do when you're on your own [Laughs].

RMB: Yes.

P3: Or else you've too much help, Oh, I'll laminate everything for you, would be my daughter's response anyway, you know. [laughs] So, everything takes, you know, ten times as long. But as I say, I'm in that position that I have the time. So, if ...

RMB: So you don't mind.

P3: I've no excuse really not to do them, you know.

RMB: Because even sort of cutting them up and putting the ..., the Velcro, that can be a bit, time consuming can't it.

P3: Yeah, yeah. But as I say, I have the, you know the time in the mornings to do it. So it's not a problem at all. You know.

RMB: Yeah, excellent, ok. So, em ... yeah ..., you mentioned already that your understanding sort of has improved since you've received the support, which has been great. Yeah, are there any negatives of visuals do you think?

P3: Em ... ah ...

RMB: We mentioned slightly the time maybe, could be a little issue sometimes.

P3: Well, yeah, I suppose maybe if you were really, you know, say maybe if I was back working full time, or something I suppose you might be more slightly under pressure. Em ..., but no, not really, I suppose it depends ... how house proud in some ways maybe you are, if you don't want to have things sticking, you know, but I suppose that's a small price to pay for if your child's, you know, happy and understanding stuff. Emm ... But no, it's

Mum involves sibling in making pictures.

Mum happy to use her time to make pictures as it helps her child understand more and be happy.

Sometimes pictures go missing.

not, and I suppose it's, I suppose just sometimes, the only thing about the PECS book can be, and actually that's what I have to do, I have to do some more jelly pictures, because eh ... obviously we're trying to get into the routine of taking the PECS book with us, because I'll be honest, sometimes we're not great, or my husband will go out and take him to Nanny's and he doesn't bring the book and I'm going, did you not bring the book with you? But you know the thing is you know sometimes you know, then you come back and half the pictures are eh ... missing.

One can forget to take a PECS book out with them. Family working on it being part of the routine.

RMB: Are missing.

Pictures can get lost.

P3: Yeah, so obviously that's, that's probably the only, the downside in terms of kind of, you know, losing pictures and stuff, or whatever. You know. But eh ...

RMB: Making sure you take the book with you as well.

P3: Yeah, making sure you take the book with you, or whatever, and em ... that you know, as I say, you come back with kind of the majority of the pictures and stuff. Stuff still in it, you know.

RMB: And would Liam use his book in other environments?

Parents feel responsible that child is not using PECS book in different environments because of them not bringing it with the.

P3: A little bit. As I say, we are trying to introduce it more. Because as I say we haven't done hugely, and that's really ... it's not actually Liam's fault, it's our fault, do you know what I mean. But he is getting better, and even, we were up North a couple of weeks ago with my family, and he was using it, like he was giving, you know, pictures and stuff to my sister and stuff, for the milk and that, or whatever. So yeah, so we're trying, you know, have it that he's going to use it, you know realise he can use this in different situations with different people and

Child is using PECS with other family members and in different situations.

Sometimes pictures go missing at

whatever and stuff. So yeah. But as I say that's probably just the only down side is kind of, if you come back and you, half the stuff is missing or whatever. Or even in the house sometimes, because like he will, like say he's, say he goes to get the milk picture, and ... the next thing his sister turns on the TV and he gets distracted. You know, the milk picture gets dropped because he's gone to see what's going on. So, you know, you can't spend kind of evenings going around ... ok, where's the juice one, or what's whatever disappeared. You know, but, that's, you know.

home as the child may drop them on the floor without putting them back in place.

Participant 5: (P5)

Interviewer: RMB

(pages 13-16 from transcript)

P5: Because sometimes, you know, like he'd ... kind of look at you with a blank face, expression, and he mightn't be taking it in. You'd have to kind of sit down, and then maybe get Alanna, his sister, involved as well and talk about what's going to happen, like, you know. And then he'd say first for doing this, second, third, and then he'd go through it then.

RMB: That's how you know.

P5: That's how I know, then because then he'd start saying it, you know, out loud, what's happening like.

Telling the child slowly what is happening first and next helps the child to understand what is expected of him.

RMB: So it involves a bit of time as well.

P5: Processing, yeah, and just ... yeah, time and just to try and make sure that it's sinking in to him, you know, so.

Child needs time to process what has been said to him.

RMB: And repeating.

P5: Yeah, repeat, repeat. That's all I do [Laughs] ... is repeat with him.

Repeating helps.

RMB: That's a strategy. That's very good ok.

P5: Yeah, yeah.

RMB: Em ..., ok, so ... since you've received the support around visuals, has your understanding of visuals, do you feel it's improved?

P5: Yeah, it has yeah. Yeah. Because I wouldn't have really had a clue like, at the start, what they were, and like you know ... pictures, what are they like, you know. I did hear about them before like, doing a couple of courses like this with the early intervention, but I wasn't really 100% on what they were but I understand now, and I understand it more so now. It kind of, was getting, I wanted to kind of know a bit more about it before he went to school last year, because they were doing it in the playschool. In the playschool where he was, he had great support and resources there as well because there was an awful lot of children with like, maybe speech problems or autistic, or whatever. So they had like, teachers, special teachers there to help the children. So they would have been doing the photographs, they would have been probably the first ones to tell me about it, but I couldn't, didn't really have that much of an understanding at the time, but ..., I do now like, you know with the school.

Mother's understanding of visuals improved following training.

Mum had been introduced to visuals through community early intervention services but she didn't quite understand what they were.

Mum took the initiative to try to understand more what they were before her child started school because they were also using visuals in that placement.

Good support in school he was at. Lots of staff using pictures in the classroom setting.

School staff first properly introduced mum to visuals. She saw how they worked in the classroom.

RMB: Good, very good, so that's ... so at the beginning you might have not known

	about them, but then once you, you really saw how they were useful?	
P5:	Yeah, yeah.	
RMB:	Were the school at first ..., why do you think like, your understanding wasn't that good at the beginning?	
P5:	Not that it wasn't I just didn't really have any knowledge about it, because in the playschool, like ..., he just went into the playschool and they had their little routine and that, but ..., like there wasn't, there wasn't any visuals ..., like there was pictures on the wall but like I said, they used photographs for visual schedules with the kids there. It might have been easier, but ..., no, just when ..., when I went to the school and they explained to me which way they were going to teach Darragh, and then I just got more of an understanding and I just got loads of information off the school about it then when he started.	<p>When mum received verbal support from the school staff she felt she understood visuals better.</p> <p>Support was specific to the child's needs.</p> <p>School offered a lot of information.</p>
RMB:	Very good, ok. So, they ..., it sounds like they had more time to sort of just sit with him, and also ...	
P5:	Yeah, ah no, yeah they did, and then when I went, I went for a little meeting, like a little kind of teacher, parent/teacher meeting last November for him, and just see how he was getting on and they would explain how he is getting on and which way they work in the class and that, so ... yeah.	Meetings with school staff help parent understand how visuals are used in the classroom.
RMB:	Very good, excellent, that's great. Ok. Do you think there are any negatives of visuals?	
P5:	No, not at all I don't. They help Darragh like, so whatever helps Darragh, I'm ... 100% behind, you know like, I just ..., I don't care what it would have to be, if I had to put them over my face as a mask [Laughs], I'd wear them all day, you know.	<p>Visuals help the child.</p> <p>Positives outweigh the negatives.</p> <p>Mother would do anything to help her child.</p>

Just once he's happy and he's understanding and ... he's not anxious or upset. I don't have, there's no negatives. I really don't think there's any negatives. If anything it just helps children ... with autism, you know, to understand, because it's just, so they can see what's happening. That's all. That's what it's about really with Darragh, and if I have to do it for the rest of his life I will like, you know. Once it helps him. Yeah.

RMB: What would you say to parents who maybe aren't as convinced to use them?

P5: I'd just say you just have to get more information and understanding about it like. And, if you can get information from the school, or like the Internet, or another parent, or someone like, if I was to sit down with somebody and say right, like you have to ..., you know, you have to practice it and you have to give it a chance like, you know. You can't just do it one day like, you know, and say oh it's not working. I never thought like that, because it always worked for Darragh. You know, I'm not saying it's not going to work for every child but ... you have to just practice and repeat, repeat, repeat. That's what it's about with ..., like, I'm more content and more like ... confident with Darragh now because he's in school, and because he got great help in the Playschool, I was just really lucky that, you see I had brought him to my Health Nurse and then she referred him to a Doctor in Cook⁹ and the Doctor referred him to the playschool, because he's on the Board, so I just went ... from the time he was two, two and a half, I knew there was something wrong, I knew ..., like he didn't get diagnosed until last year, but I wasn't a bit surprised when the child psychologist, from the early intervention team told me ..., like, what he has. I was already after doing research on the

Visuals help child become less anxious, upset, help improve understanding and increase happiness.

Visuals help a child 'see' what's happening.

Happy to continue to use visuals for the rest of the child's life if it helps him.

Visuals always worked for her child. Practice and repetition helped child grasp the concept.

Mother is happier and more confident following the support she has received.

⁹ Fictitious name

computer and all the things he was doing and the symptoms and all, and everything was just autism. Now, not that I, I didn't go around saying it to anybody but ... in the back of my mind, I always knew that's what it was and so when the child psychologist said like are you upset, I said no, because I've been crying the last two, three years, and being upset you know but, ... now, ... like I'm in a better position to be like kind of stronger for him. But, when he was a baby and he was ... upset, and I didn't know what, and he wasn't doing the same thing as Elena¹⁰, in my mind I was always comparing him. Like Elena did this, and she was talking at one and a half and she ..., she was just really quick and advanced, everything just came real quick with her. Like, she was walking and talking and ... and then when he wasn't doing it, and he was sitting there on his own and ... wasn't playing and he was really kind of ..., you know, distant from everyone, I just knew straight away, it wasn't, not that it wasn't, I don't like to say the word normal, but it wasn't ..., it just wasn't typical baby. Now he'd hug and kiss you all day now, but when he was a baby no affection, he would not show you ..., he wouldn't kiss or wouldn't hug you. He didn't want you to hold him. He always wanted ..., I just knew there was something different and ..., just once he got a little bit older and he started getting more help ..., that's when I started getting more information, because I just ..., I didn't know what was wrong with him when he was younger and

RMB: So the information has been helpful.

P5: The information, but people just have to give it a chance. I don't know anybody, I'm sure there is people that don't particularly like the visual schedules, but I'm 100% behind them, and it's just, you just have to get information and if you

Information on visuals was helpful.

Obtaining the information on what they are and giving visuals a chance is what helped mum to

¹⁰ Fictitious name

can't get the information on the Internet, get the information off a teacher, or someone that, a professional that, even a Doctor or anything that

use them.

RMB: And, why ..., I'm just trying, this is what helps me understand like ..., what parents go through, I guess, but why do you think some people, some parents refuse to use visuals?

P5: I think some parents refuse to use visuals because they are probably just ignorant to it, or they just can't accept that their child is the way they are, and the reason ..., I'll give you an example, the ..., I went to a talk there a couple of weeks ago with the Early Intervention, they just sent me a letter. Even though I'm not with them, they sent me a letter about, information about autism, a 4-week course. Now I only went one of the weeks, as the other week I couldn't go, but there was parents there, that had children that were autistic, and everyone was telling their story and everyone was listening. It wasn't about judging anyone. Everyone was listening. And there was parents there, and when I left the meeting ..., I said to myself like what is wrong with them. They just can't accept that they're autistic, they just can't accept it like. I know it's probably harder for some people, but I felt like getting up in the class and saying, well you have to accept it because that's the way they are and no matter what you have to, it's not their fault that's just the way they are, and it's never going to change like, you know. I just think some people are ..., they don't ..., like ... they are just ignorant to the whole ... understanding of it, and it's not do you know what I think it is, and one girl said it as well, in the meeting, that it's not that the people are probably ignorant about it, or don't want to talk about it, it's family members and other people in their family are like judging them, and judging their children and you know, this is what I'm trying to say, with a

Mother thinks the reason some people choose to use visuals is because they can't accept their child's diagnosis or are unfamiliar with them.

family circle, they're saying like what's wrong with him and there's ..., there's something wrong with that. Like, making the child out to be a monster. Like, you know some of the parents and they were devastated, they were crying and they were upset and all, and they were saying I just can't accept it, and it's probably hard for them, because they're probably not getting the support that they need off family. Like, I mean, my dad is 78 this year, and he's only getting an understanding of it now. At the start like, he didn't know what it was, and like he's wearing one of the autism bands now and everything, but you have to sit people down and talk to people about it, because people are just ... they are not getting the information and you know the way, especially older people, older generations think like, if a child is having a tantrum in a supermarket it's like, they're bold, they're a bold brat they are, and ..., like I can sympathise with a mother like ..., because Darragh has done it a gazillion times to me, and I feel like jumping down on the floor and doing it with him [Laughs], but ..., like you know, when I see it in other, ... even if a child, a normal child, I always have ..., I always say oh god that poor mother over there.

RMB: Yes.

P5: I know, I kind of know now if a child was like Darragh in a supermarket, I'd ..., you know if you see them, and you'd see them and I'd say that little boy must be autistic, or he must have ..., I would just be able to see the kind of, the way he's going on, I'd be like that was like Darragh, and I'd never stare and I'd always say, or you'd feel like going over, going, you'll be alright, but people are so judgemental. That's what it is. I think it's, people don't like it because ... I think other people might, they might be afraid that people might judge them for doing it, and ..., you know like because there is people, like,

that have their children that are autistic or, and there's family members, like older generation, even young people as well ..., people don't understand it like. They just feel if they can get information before you start judging, you know?

RMB: Yeah, and do you think it makes children with autism look very different if a family uses visuals with them?

P5: Not really, no, because I have friends that have kids that aren't autistic and they said Jesus, give us a few of them beyond in the house. They actually say it's actually good for ..., they actually said it's actually, one of my friends said it's a brilliant idea. She says I think I should get something like that and stick it on my fridge. Because it's about routine and it's about telling the, it's like structure in the house.

Visuals don't necessarily make a family look different.

Visuals help keep routine and structure the home.

Participant 6: (P6)

Interviewer: RMB

(pages 17-20 from transcript)

RMB: And tell me a little bit more about his communication. You mentioned like he's using more words now?

P6: Oh yeah, we're using lots of words now, and we've even expanded, I mean I even told his teacher this morning like on Saturday morning he came in to me and he said where is my iPad. Now we've never heard that before. Two weeks ago, one day I wasn't here, he asked where is my Mum? So I was like, he said what? Like, we've never, so he's ... it's just expanding constantly. His vocabulary is

Child is using more words and sentences have increased.

Child is beginning to ask questions.

Child can now label pictures.

just coming out, you know ... emm if you show him any book, if you're going through anything he has the words. Like he's just, the words are coming out constantly, but it's now the structure is beginning to come into it. So the obvious, the big one would be, I want A biscuit, so that's the recent ones.

RMB: Forming sentences.

P6: Yeah, so I had, Caroline was here, from ZZZ was here with me, about two weeks ago, I had asked her to come out because she hadn't actually seen him since he started to talk, and I was using bits that Fionn his twin, or Erik sorry, his twin was very slow to talk. So I had got lots of exercises and work sheets from the Public Health Nurse and the Speech and Language Therapist in EEE at the time, so I was kind of using them with Fionn, so they would have been more, you know ... you'd be asking them to show me the t-shirt or stuff like that, so you were trying to gauge his comprehension. But I was asking Caroline, so Caroline just gave me the most simple thing which was if he says three words, you add a fourth. If he says five you add the sixth. So, it's like, I want the ball, it's red, I want the red ball. So that's what we're doing. So last week the swing is now the red swing, or the green swing.

RMB: Oh very good.

P6: So that's you know, and he gets it. You know, he's, he ... he doesn't, like if you, if you put Fionn, and he's like this on everything, if you put him in front of a new game, he doesn't know what to do with it. Whereas his twin Erik will plough into it, right. Fionn, you show him it, how to do it, he will do it. Erik, you show him how to do it, he'll still plough into it the next time and still look for your help, because he'll just plough in, you know, whereas Fionn sits back, takes it all in.

Parent invited therapist to come home to observe her child.

Parent used worksheets given to her previously.

Parent asked therapist how to work on increasing her child's language skills.

Child is now using more speech following recommendation by the SLT.

Child demonstrates preference for modeling how things are done and then picks up quickly.

	You show him what he's meant to be doing, and then he'll just go ahead and do it.	
RMB:	Excellent, excellent.	
P6:	Now on certain things. There's ... if you were to give him a verbal instruction on it, he won't get it. It's visual. The practical, showing him the bits and how they go together.	Instructions need to be visual for the child to understand easily.
RMB:	Yeah, so, I mean in terms of his communication I guess, he's not only requesting now, he's asking questions?	
P6:	He's asking questions, yeah.	Child is asking questions.
RMB:	He's using adjectives in his speech as well.	
P6:	Yeah, he's coming over, like he's looking for tickles. Like, since Christmas he's been looking for, he'd come over and he'd use PECS, like I have a PECS there for a hug. And a swing, you know this kind of, a twirl. Whereas now he'll come in, and particularly to Roy, because Roy after tea tends to do horseplay, and he'll come in and he'll go tickle? And that's him, he wants to be tickled. And he'll come over like this to you and he's waiting for you to do it back. So, it's ... you know, we are expanding.	Child will request for 'tickle' using words. Child will request using PECS.
RMB:	And more social ... social play as well.	
P6:	Loads more social, yeah. Things like he'll come in, I see you! This, you know, and that's all from games of you know, running around the house and ... where's Fionn, pretend that you can't see him. This kind of thing.	Increased social play and joint attention noticed.
RMB:	So do you feel like his sort of joint attention has improved as well?	
P6:	Massively. Massively.	
RMB:	He's more available.	

P6: Yeah, far more available. Now he's still, he is obsessive about the alphabet. It's like completely and utterly, it is an obsession. We really need to ... hold it back, or make sure it doesn't interfere too much. But if he's not on that alphabet train, he is with you. Which is what we never had. Like we never had that from him before. Now if he's on an alphabet thing, you actually have to let him go to Z. So if he's on the alphabet, it doesn't matter what you try and engage him with so now I've learned is, we get to Z and then we go. So, you actually let him finish it out, he gets to Z and then he'll go on. So it could be ... like he does things like musical instruments, he does it A to Z. So he's like accordion, banjo, whatever, and this is the way he works, and then monkey, or animals and he'll start with, you know and you have to let him get to Z because otherwise ... you are actually at nothing. So it's trying to make sure that that doesn't interfere with everything else that's going on.

Child is obsessed with alphabet.

RMB: Well I guess it's good that you're doing that, because there is a sense of you know ... a clear beginning and ending.

P6: That's it, and you don't let him start the next one. You know, it's like, that's it, we're finished, it's finished. There might be a little bit of a 'nnnhhh' throw himself to the ground for a minute, but he quickly moves on. You know, as long as you're ready to move to the next task and show him exactly what it is. If there was the gap, he'd be back in.

Finishing a preferred activity by saying 'finished' and moving the child onto another task works best.

RMB: You could almost have a little picture of the alphabet almost.

P6: Yeah, we have, they are around in lots of places. The last one actually I saw it at the bottom of the stairs this morning. Yeah there is alphabet symbols and ... [laughter]

RMB: That's brilliant that he's able to manage though and ...

P6: Yeah, he does manage. I mean ... you know there's some days it's not as easy as others, but that's ... everybody.

RMB: Every child ...

P6: Exactly, yeah. Everybody is the same in that respect, us included. You know, but he ... no, he's good. The language is ... and the language has made a big difference even from his interaction with the lads. You know Erik and ... Karl see him differently now. They interact with him differently, because he's got a few words. Which again ... is massive.

Child is more interactive with siblings.

Siblings 'see' brother differently now that words have come on.

RMB: It's nice for them to see that as well.

P6: Yeah, exactly. And the other thing on the visuals there is like ... I don't know, I think all kids seem to be obsessed by iPads and Minecraft and all this kind of stuff, but he, he just seems to get them. He gets them, like he works out stuff instantly. Like, to the extent that Erik would be looking over Fionn's shoulder going how did he do that? You know?

Child enjoys the Ipad and visual games such as Minecraft. Child seems to work out how they work instantly.

RMB: Is he into the games as well, Fionn?

P6: Yeah, they're all, and I mean Fionn goes onto an iPad and goes into YouTube and looks up ABC songs, that's what he does. He'll go and he'll get your phone. If you left your phone, huh, YouTube, ABC songs and that's what he's doing. And he can work his way around it, like he can find what he's looking for. Whereas Erik might be more inclined to come over here and say Mum will you find me, whatever it is. Whereas Fionn just goes in and pop ... types it in himself.

Child knows how to navigate an Ipad and Iphone easily.

RMB: Yeah, so he's very visual with the iPad as well?

P6: Oh yeah, yeah. A lot of the stuff I have on his would be things like, it would have started off very basic ... and a lot of them would have been alphabet now that I think about it. But there would be a lot of stuff on shapes and that whereas now he likes to go the more musical route. Like he's ... I'm actually, we're trying to see can we get, I'm trying to see can I get someone who would teach him the keyboard, because he seems to be really, really into music, and he would sit down, there's a toy keyboard thing, but he sits down and he ...

Mother adjusted ipad games according to child's level.

Child is interested in music and alphabet apps.

RMB: Oh for playing the instrument.

P6: Yeah and I think the way his mind is working, they've a great little book in XXX, which I haven't been able to track down here, I can get them in the States, they're like a keyboard book that has, you know the letters on it. The notes. And ... the notes are then ... so they have them written in proper musical format, but it has also got the letter, so it's C.

Mother trying to expand on child's interest in music by using other activities that she feels the child might be interested in.

RMB: I think you can get that as an App on the iPad.

P6: Yeah, you probably can.

RMB: The keyboard.

P6: Yeah, because he loves it, like he, he really loves it, and I just think that ... you know, if somebody was, had the right frame of mind with him, I think they could get him to learn ... I think music, because music, they kind of go hand in hand. And reading music is quite structured.

RMB: Definitely. And the piano would be quite structured.

P6: Yeah, so that's what I think you know, it's ... well hopefully ... we are going into the music school this evening, Karl's in there

<p>for guitar, so I'll just see if they've found a name for me, but ... and again, this is where I suppose I would ... try and get people to come here, where I can have the visuals and everything in front of him, and it's the same place, because if we go to a music school, to a strange room ... Fionn will spend a half an hour trying to get out the door, as opposed to actually sitting down to do the piano. Do you know that kind of way. That's where the distractions of new places ... and it doesn't matter how many photos I take of it, it would still be a new place.</p>	<p>The child feels comfortable being taught in the home environment.</p>
<p>RMB: Yes, there's so much going on in a new place I guess.</p>	
<p>P6: There's too much going on for him to sit down and absorb something else, but yeah, I mean if we can get him, fine.</p>	
<p>RMB: Yeah, so that, those were actually my last questions. It's just if there was anything else you wanted to tell me about visuals. It's just 11 now, so.</p>	<p>A new environment can be very stressful for the child even if they are prepared with visuals beforehand.</p>
<p>P6: Oh great, lovely. No, that's it ... it's fairly limited what we use them for now. Because we don't need to use them for everything anymore.</p>	<p>Pictures are not needed for everything in the child's life as the child has now improved.</p>
<p>RMB: I think you do use them in a lot of different ways. Like even just thinking of your schedule in the bathroom, you know that's something that you were working on, so ...</p>	
<p>P6: Yeah, that's constantly used, I mean that's the ... and everyone whose involved with Fionn would use that. [goes to bathroom to get schedule] so like it's you know, it's the same and a picture of Fionn and toilet and all the rest, and then this is the only one that would change, sometimes it would be an easel board, sometimes it would be something else.</p>	<p>All the siblings in the house are familiar with the child's toileting schedule and would also use it.</p>
<p>RMB: Oh he gets a reward at the end. Yeah.</p>	

P6: Like, it's funny, sometimes he puts hug there.

Visuals can be used to help the child understand his reward after an activity.

RMB: Oh does he, ahhh.

P6: He's a real affectionate little thing. He'll go, and he'll get the hug and he'll stick it there. But like I've got stuff, I don't have them in his bedroom funny enough. Because I don't need to. He takes everything off the walls in his bedroom. And he has finally started to stay in his room for longer. So, we've kind of again, that's where I kind of made the decision do I want to keep that maintained, or not. So, I didn't do it, and you know, he's surviving and he's fine.

Child will request 'hugs' using pictures.

Pictures are no longer used in the child's bedroom as parent felt the child was better off following reflection.

RMB: Super.

P6: Whereas this was kind of a biggie, it needed to be, it needed to be kept up ... I don't think there's anything else.

Participant 7: (P7)

Interviewer: RMB

(pages 2-5 from transcript)

RMB: Did you do any of your own research?

P7: Em ... not really, I mean, like as I said, any of the pictures I would have got ... actually no, I did a few, like I would have printed off some pictures myself, like that. For different activities, like, if we're going on holiday I wanted one of an airplane, a specific one like that. But then since then, no I tend to re-use the same ones really.

Parent obtained pictures from professionals or printed them off herself.

RMB: Excellent, excellent, so you found the

	professionals gave you most of the pictures then.	Professionals gave parent most of the pictures.
P7:	Yes, yes.	
RMB:	Ok. And you mentioned at the beginning you weren't so sure, you know if visuals would work for your child. But once you made that decision, sort of how satisfied were you, with the decision?	
P7:	Well, I suppose it's been trial and error, like, I mean I have had, I don't have any visual, I don't do a daily visual ..., like for the house anymore, ..., because I found that ..., no actually having said that, sorry, I did have one ... and one of the professionals, the ... the early intervention team said I had too much detail, I had too many pictures going on. And I had thought to myself that Eddie took no notice of it. So it was as if it kind of, it became a background thing. So I got rid of that one, and then I got a more basic one, which as I said, I would use like, ... for an unusual event. So I don't really use it on an everyday basis. I do have one with ..., now that he ..., as I said, we've had at different stages different ones. I suppose that's the clearest way to say it.	<p>It's been trial and error with the use of pictures.</p> <p>Parent doesn't use a daily visual calendar daily anymore. She did have one but professionals said it was too detailed and also she felt her child took no notice of it.</p> <p>Whilst the daily calendar was there, parent felt it was being ignored by child. However, she then made an easier one to follow, which she uses for unexpected events.</p>
RMB:	Yes, and sort of, were you satisfied with it, like what changed, what ... convinced you to work on them, I guess?	
P7:	Em ... well I think, the ..., the team, like, any of the members of the team would feel very strongly despite the fact as a parent you might say yes, but my child is verbal, they seem to be ..., one of the things they try to promote really does seem to be the visuals. The use of visuals. So ..., the main problem that we did have like that, would be trying to ..., I noticed that yeah, it was the problem of something different, an event like that, something that was ... something new, so it has worked, so I suppose I use it, like I said I don't use it every day because I	<p>Professionals felt strongly about using visuals despite the fact the parent might have disagreed because their child was verbal.</p> <p>Parent felt professionals try to promote visuals.</p> <p>Parent found that visuals worked mainly when there was an unexpected event happening in the child's life.</p>

	<p>don't think it's necessary, but I would use it now, for example, if we were taking him ..., I don't know, to the circus, or to something like that, to say, this is the order. And even, like, if you, ... you know, at the beginning you have the impression that he barely looks at it, but then I have noticed now he does kind of, it seems to be he's processing it like. So I kind of ..., I still would take it, and I would take like the A4 sized thing in my handbag, even if I wasn't, even if I never used it, you know.</p>	<p>Parent doesn't feel it necessary to use the schedule everyday.</p> <p>The child may not look like they are interested when they are shown pictures, however the parent began to notice it was actually working.</p> <p>Pictures appear to help the child process what is being said to him.</p>
RMB:	<p>Very good, so you have it there just in case?</p>	<p>Parent would still carry the visuals around even if not needed in the situation.</p>
P7:	<p>I would have, yeah, if I knew, what would you say, special events and things like that. Like if we were going to a wedding or something unusual, you know. So that he would, I think that's when I realised like you know, like a thing like going to a wedding, or even ... something that isn't tangible, something that ... like for us, we kind of understand, or my other son would go with the flow. But for him I could realise that it's like this thing that has no shape, no end, beginning or end to it. So to put a kind of a beginning and an end and a middle to it, I find that useful, yeah.</p>	<p>Unusual events can be broken down with the use of visuals. The child therefore can understand that there is a beginning, middle and end to an activity. This appears to work for the child.</p>
RMB:	<p>Excellent. So at first maybe you weren't so sure because ... they were ..., your child was verbal, but then ... you noticed that for those kind of changes and so on, that it is helpful for him, for those instances then.</p>	
P7:	<p>Yeah, it definitely, like I said, I've noticed that yes, it would work. I think, as a parent, if he doesn't need it on a day-to-day basis, and I didn't want him either too to be too dependent. I think as a parent you think, that's what happens, you put the structure in place, but then you realise sometimes you're stuck with that. So I, now, I suppose that I'm a little bit better informed, it's getting that balance.</p>	<p>Parent noticed that visuals do work for her child.</p> <p>If the child doesn't need it on a day-to-day basis then it is not used.</p> <p>Parent felt using visuals regularly may make the child dependent on them or too dependent on</p>

	<p>You know, that I use it, I have it there as a backup plan. If it's all going horribly wrong, or if I think he's very agitated or upset that day. But otherwise, I suppose I'm trying to reduce the use of them really.</p>	<p>structure.</p>
RMB:	<p>Yes, and would you use kind of verbal prompts as well?</p>	<p>After the parent was more informed, she feels more able to try to balance between needing them in certain situations as opposed to using them all the time.</p>
P7:	<p>I use a lot of now and then, and first, and it's funny because even his brother who's younger says things to me like, yeah first we'll go to the cinema and then we'll eat the sweets. So I, you know, and I try to get my immediate family to do that as well. Just something, you know, say it's harder with the grandparents because it's kind of hard to get them, to reduce their speech. You know, but I've said that as well to like say, at the swimming pool with the swimming instructors. I, I think I can get a vibe now quite quickly of people that have some knowledge of kids with special needs, and some people that are really well meaning and they'd have no knowledge and they do look a bit, ooohhh, you know fear is in their eyes. So I just kind of usually I say, well look, can you reduce your language, keep it very simple and you can try the first, now and then.</p>	<p>Parent will use them as a back up plan when needed.</p> <p>Parent is trying to reduce the use of visuals.</p> <p>Reducing speech helps the child understand instructions.</p>
RMB:	<p>First next, yeah, yeah, excellent ok. And you know what was the most helpful about the support you received around visuals?</p>	<p>Parent has informed others around the child of the communication strategies she is using.</p>
P7:	<p>Em ... I suppose when they said the idea of, to reduce the anxiety. To use it in that sense, because I hadn't really seen it, I hadn't thought that Eddie actually was anxious, and it's only now that I've done a few courses that I can see that he is probably anxious about changes. You can see that look of fear across his face. So if it helps to reduce the anxiety, that's why I probably tried it first.</p>	<p>When professionals told the parent that visuals help reduce anxiety, she didn't particularly think her child was anxious.</p>
RMB:	<p>Very good yeah, excellent. Ok. And ... you</p>	<p>Following the information through parent courses, parent can now see that her child is probably anxious when there is changing happening in the child's life. She saw 'fear' in her child's</p>

	<p>know, was the support ... through other parents helpful during the Early Bird around visuals. Were you sharing any ideas, or?</p>	<p>face and therefore decided to try visuals.</p>
P7:	<p>Not so much with other parents. I think we asked, like whatever, excuse me, whatever we asked for like, for example, some of them might have wanted help with toileting or the food, or ..., whatever we asked for we got, in terms of like the laminated pictures.</p>	<p>Professionals provided any pictures parent asked for.</p>
RMB:	<p>Yeah, excellent, very good. Ok, and in terms of the support again that you received, you know, were there any negatives? Are there any negatives that you'd like to mention? Do you think that we should be providing parents more, with more information around visuals? Less? You know, because I guess, as a professional, you know that the visuals work, but they have to be applied, you know everybody's situation is different because every child is different. So sort of looking at the support, like should we be providing more, less, or should we be providing it in a different way?</p>	
P7:	<p>I suppose, as a parent, sometimes it seems to be, the main thing that's offered, and it's usually the first one, if you ..., like, you know, I've noticed that, that if you do say I'm having a problem, like we have problems with sleeping patterns and we've problems with eating, and it's always the first thing that's offered. But like, when you know that it exists, I suppose sometimes you wish there was an alternative? Do you know, or like maybe that it wasn't ..., the other alternatives would be offered, not just the visuals, does that make sense? You know, because I had read, from doing a little bit of reading myself, that children with autism are, you know, visual, very visual. But then after that I read a book about a parent, and she ..., you know, she had the opposite view, that yes they are visual,</p>	<p>Visuals seem to be the first and main thing that is offered sometimes in terms of support.</p> <p>Sometimes you wish there was an alternative.</p> <p>Sometimes you wish the professional offered alternatives not just the visuals.</p> <p>Following research carried out by the parent, parent understood that not all children with autism are visual learners and therefore</p>

but most, sorry, that most of them would be visual, but then the minority that are not visual get stuck into the same category. So I was just thinking other alternatives, you know, now it seems to be, as they get older, it seems to be the social stories. But I suppose as a parent you feel frustrated because you would imagine that there is some other little magic cure that is there somewhere, that maybe you're not being told about. But I think really it does seem to boil down to, use of visuals, and social stories. And when they don't work then you're a little bit like

those that aren't particularly visual get stuck in the same category.

Parent felt frustrated when other alternatives, other than visuals, were not provided. Another 'cure' that possibly professionals are not telling you about.

When visuals do not work it can be frustrating if there is no other alternative.

RMB: Have they ever not worked?

P7: Well for the sleeping pattern I can't, we have ..., we have periods when we go through like, difficulties with sleeping, and we have never found a reason for that, or, we've cut out DVDs or television in the evening. So maybe the visuals don't really apply in that category, in that problem.

Visuals haven't helped for sleeping issues.

RMB: Yes.

P7: But, no, I mean anything, like I said with the visuals, for the daily schedules, ... that seems, like for now for example, we've moved on to say learning the days of the week. So I have a calendar, just a very basic calendar that I got with the numbers on it. So that's kind of working to, at the beginning I thought, oh gosh it wasn't a good idea because the numbers were on it. But it actually is now, because we're going through the months as well, as in like, we get to so many days. So, we've kind of moved on to that like, and particularly I just highlight the weekends and the holidays because my son is quite anxious. He likes the idea of the holidays, but we need to do the same thing every holiday. As in, go to granny's house. So I suppose I've moved on to that, that kind of visual.

Visuals have helped as a calendar to teach the days of the week.

At first, wasn't sure of the visual calendar that the mother had for the child because of the use of numbers and the child's interest in numbers. But after using it, it worked well as the child now understands the concepts of months.

Visual calendar works for explaining holidays and weekends due to the child's anxiety around these.

RMB: Yeah, so I guess you are using ones that sort of suit Eddie, rather than ones that just maybe, you know, have just been recommended to you. As in you've adapted them according to his needs really?

Child enjoys routine during the holidays.

P7: Yeah.

Adapted according to child's needs and age.

RMB: Very good.

P7: For his age, I suppose.

RMB: Exactly, exactly, yes his age. Ok, yeah, so the next set of questions are around your understanding and ability to actually use them. Ok, so, what can you tell me about your ability to use them, following the support you received?

P7: As in, did I find it difficult to use them or ...?

RMB: Sort of how has your ability changed, since the support? Like you obviously got to know about them through the Early Bird. So now, kind of, your ability to use them now ...?

P7: I suppose now I would ..., like I said, I suppose ... yeah, I suppose now I would almost try to talk as well, because I mean, my emphasis now would be trying to improve the speech, because that's a weak point for him. So I suppose speaking and, I would use the I suppose, as not just as a visual aid, but also as a, what would you say, as a support for speaking.

Visuals are used to support spoken language.

RMB: Ok, for expressive language?

P7: Yes, like that. Learning the numbers and the days of the months. Trying to expand it a bit, and not just say ..., I mean, I use the now and then, first and then, but ... when I have the calendar and we kind of talk about this is the holidays at the weekend, I try, if I think of it myself, to

Visuals are being used to teach numbers and days of the months.

Visual calendar used to increase child's vocabulary. Mother uses it

	expand my own vocabulary as well like, you know.	to help her use different vocabulary with the child.
RMB:	So how confident do you feel about using visuals now? Kind of, when compared to when you first heard about them?	
P7:	Yes, I mean, like I said I would, I ... I would be quite happy, quite confident using them, as necessary. Like I said, I think we probably skipped a phase, of maybe, you know, putting up names on objects in the house. So now it's really only like for changes in our routine.	<p>Mother happy and confident to use them after support received.</p> <p>Visuals used as necessary, especially for changes in routine.</p>

Participants: Group (G)

Interviewer: RMB

(pages 7-11 from transcript)

RMB:	Good stuff, yeah.	When using visuals you don't realise that the child's siblings might be wondering why you are using them with their brother/sister.
G:	But we were kind of ... yeah, you know, when you're doing ... you don't realise. And the others are ... why, why are you preferring him almost? You know.	Using visuals with one sibling can be seen as almost preferring that one child. Siblings may ask why their brother/sister is being 'treated' differently.
G:	[Laughter].	
G:	And if Tom's twin sister asks me exactly the same thing, Mum, do you love Tom more than you love me? You know.	
G:	?? 21.37 [unclear] ask me that.	Siblings may feel like you are giving extra time to their

G:	<p>And I said absolutely not fairy, you know, but that's how they feel because they think you're giving that time with the visuals, ... they are things that people don't tell you. You're doing that for the best for your child because you think that that's what they need ... There has to be a support system around everybody else, and then you learn yourself to bring everybody into it, you know. Like ... you know, if we're all doing something, we're all doing it. I don't treat Tom any differently than the others. I might have to use simpler language sometimes, but he gets the same as everybody else. If he's wrong, he's wrong. If he's right he's right. And I think that has stood to him, because he knows. Regardless of anything else, you don't get away with it. You know, you do the right thing, or you do the wrong thing. And if you do the wrong thing there's a consequence. But, when you're first starting off and you're focusing on doing the right things, the others then feel like, oh no, ... what did I do, why am I not getting to be part of that? Why am I not involved? They see it as a special thing.</p>	<p>brother/sister with ASD when using visuals.</p> <p>As a parent you may be oblivious to the fact that this might happen because you just think of doing the best for your child and think of what they need.</p> <p>Visuals need to be implemented by considering the family's needs and not just the child's. Parents themselves sometimes learn to adapt visuals to suit the family's needs e.g. using visuals with all the family.</p> <p>Does not like to treat the child differently.</p> <p>Visuals can be seen as a 'special thing' by siblings. Why is the child with ASD getting away with certain things?</p>
RMB:	True, yes.	
G:	<p>So, it's to teach that, yeah ... you need to focus on this with autism with the visuals, but bring your other children in, so that they can feel a part of him, of being involved.</p>	<p>Visuals need to be understood by siblings so they too can feel involved and participate.</p>
G:	<p>Actually, that wouldn't hurt as advice when PECS is being introduced to parents, to just be aware that yeah, the sibling aspect of it.</p>	<p>Parents need to be aware of sibling's aspect when training them to use visuals.</p>
G:	And it does have an effect.	
G:	<p>It does yeah, definitely. And then you're thinking ... oh, I've been terrible. You know, because you do kind of get caught, you're printing stuff off and you're</p>	<p>Using visuals has an affect on siblings.</p> <p>Parents feel 'terrible' if more</p>

	laminating stuff, and ... the other young fella is saying, what are you doing? You're hours doing this like you know, and you say ah yeah this is for your brother. And he's thinking, well what's for me?	attention is directed towards the child with ASD e.g. seeing the parents laminate pictures etc.
G:	I'm still here.	Siblings may feel like a lot of time is being spent on the child with ASD when parents are using visuals.
RMB:	Very good, that's great information. So the next question is around your, sort of understanding and ability to actually make them and use visuals. So what can you tell me about your abilities to use them now, like, kind of compared to when you were first introduced to visuals?	
G:	?? 23.42 [unclear] have a concern, because of he understand, and we do expecting him to understand and some day expecting to hear ?? so I don't know what to do. He's ?? as he need to ?? pictures, take off and see how we react with that.	Parent concerned whether visuals should be removed if the child now understands them.
RMB:	Ok, so in terms of ... whether he still needs to use the PECS or not, is it?	
G:	Yeah.	
G:	Well, I'm kind of of the thought that, leave them on the wall, and that way, although we're not referring to them as often, I still think he gets ... an idea. Because a couple of times where he'd be a bit upset, and I wouldn't know what's wrong, and he'd go over, and it would be, he wants his socks on. And ... I wouldn't have figured that one out [Laughs] by ...	Other parent recommends keeping them on the wall. Even if they are not being referred to by the parent, child still can use if needed.
G:	Can he tell you, I want my socks on?	
G:	Not really.	
G:	Ok.	
G:	His language is starting to come on, but	Visuals have helped improve

	sometimes he gets upset and you haven't a clue what's wrong, and it might be something as simple as, when you're taking him out, he was asleep in the car one time, and I was taking him out ... and his shoe fell off. So ... I just took off his other shoe. But he didn't, he wanted both his shoes, back on, and then ... take them off.	expressive language skills.
		It can be sometimes hard to understand what they child wants with little verbal language.
G:	Yeah.	
G:	And that was kind of the process he wanted. But he was getting upset until ...	
G:	He could show you the picture.	
G:	Yeah, and I went right, there we go. And then he's fine. And I went, they're staying.	Visuals helped the parent understand the child's requests when verbal language was limited.
G:	And he can't say my shoe.	
G:	He can say shoe.	
G:	He can say shoe.	
G:	He has a limited vocabulary, but not so much with sentences. Like we're only in the process now of him starting to say, I like ..., you know ... I like, ice cream, bananas, whatever, you know.	
G:	So the thing for him is, he understand, and sometime he can say, but suddenly sometime the same words he say every day. Often, but suddenly he like go blank. Can't speak it out, what he want. Yeah.	Child's vocabulary skills are developing.
RMB:	So the visuals, you are really using them as a prompt, to encourage him to use more ...	
G:	Language.	Visuals being used to help with understanding of situations and increase verbal language skills.
RMB:	Language I guess, yeah. And it increases understanding of situations I guess.	

G:	And we have a kind of, a key ring printed out with, you know ..., no hitting, no shouting, that type of thing. We left that over in the ..., my parents house, so when he was over there. If he, because you know ... you need to get away sometimes and me Da wouldn't have a clue, so he has this. No TV, TV off now, or ... you know, no shouting, no crying, that kind of thing.	Parents use a key ring with printed pictures to help the child understand certain rules such as 'no hitting'.
RMB:	How do those pictures work for you?	
G:	Yeah, I found them useful ... definitely. Because you can't keep saying, stop, stop, stop. And then you're thinking, it's not working, and I found, even for me self, to keep me self calmer [Laughs], you know, it's just there we go, there's the picture. You know, and then eventually kind of, with everyone being calm it kind of sinks in and yeah ... move on from that.	Key ring was useful as it reduces the amount of times you have to keep telling the child to stop doing something. It also helped the parent feel calmer as parent can just point to what they mean. Child is more able to follow through if everyone is calm and language is reduced.
RMB:	Do you guys make your own pictures, or	
G:	Yeah, Google Images or anything I see. The phones are great, because you can expand it and take a photograph and then just download whatever you want.	Parents make their own pictures. Google images is used as well as photographs.
G:	Print if off, yeah.	Images are printed off easily with use of phone.
RMB:	What about you Clara, do you have?	
G:	Yeah, I have an App on my phone that you can make your own, so a lot, what he's used to, like ... you know, I'd take an actual photograph and use that, and then you can print them off, and then I do take, like no hitting, all that from Google. I just Google a lot of things [Laughs] and then I get it from that.	Apps on phones have been used to make pictures by parents.
RMB:	Because you almost have to be quite a high tech person, I think.	You learn to use technology as you go along.
G:	Yeah, you kind of learn as you go on. Laminating, all this.	

G:	Dealz is just a fantastic shop, and Tom loves to create, so ... we buy the little hands and the circles and all that, so where you're saying no, no, so we have a little hand and it's on a lollipop stick.	Parents use arts and crafts to create their own way of making visuals for the child. Use the child's interest of crafts to help create his own visuals.
RMB:	Very good.	
G:	And one is painted red, and that means, that's not good hands, and then the green one, and then we have the traffic lights. You know ... and then sometimes you know, I'll say where are you now on those traffic lights Tom. And he might come in and point at the orange. And I'd say do you need some time by yourself, and he'd say yes Mum. And he'd go and have some time by himself.	Red hands to indicate 'no'. Use a traffic light system to help the child understand their emotions and the way they are feeling.
RMB:	Great.	
G:	Or I might take out the red one and say Tom, ... enough. And he'll say, Oh I'm sorry Mum. You know.	
RMB:	That's a great idea for the visual. Because that is a visual. You know, with instructions.	
G:	Yeah, so with him being involved in creating them, and the other two, they get to create at the table. So we do art. But it's ..., it's a learning process of art, it's not just ..., you know, anything. So we do a lot of that kind of stuff.	Child is involved in creating his own visuals. This helps include siblings. Creation of visuals is seen as an art activity by those involved.
RMB:	That's great.	
G:	Or we have faces, and like happy and sad, and stuff like that. ... So, yeah, that's how, that's where we are now. But you know, we weren't there.	Visuals can be used to teach emotions.
G:	You are now, but we are going ?? 28.36 [unclear] nowhere.	Parent feels like child is not making enough progress still.
G:	And you will be there, you know, you will be there. Or like, we show pictures,	Visuals can be used to teach the

	we're trying to get Tom now at the moment with the visuals, we're using them more as in ... like I'll show him a tap, and I'll say the tap is in the ...? And he'll say, the kitchen. And he'll then say, he'll repeat back, the tap is in the kitchen. You know, to extend ...	child to understand and learn new vocabulary.
G:	Yeah.	
G:	His sentences, so I'm saying it for him and let him say it. And then the next time I might just hold up the picture, and he'll say, the tap is in the kitchen, without me saying it? So that's what we're working on now, is extending his sentences.	Visuals are being used to increase the child's expressive language skills. Parent models speech by using speech and pictures at the same time.
RMB:	Yes. And Clara, yeah, tell me kind of ... a bit about your ability to make the visuals now, compared to sort of when you first started doing them I guess.	Visuals can be used to prompt speech.
G:	Yeah, well, a lot of them went in the bin [Laughs], because you know, I didn't have a laminator, never had a laminator. So, some of them are more like, just literally stuck onto backs of cardboard and were a bit, you know, not the best at all. And I actually still have one or two of them with the popcorn on it, and things that I have kept. But ... now, I'm an expert yeah, laminate it out, have it all, you know the sizes and whatever.	At first it took practice to make pictures, a lot were binned. Parent did not have a laminator at first. Used cardboard and stuck pictures to that. These weren't practical so parent bought laminator. Parent now an 'expert' at laminating, printing and sizing pictures.
RMB:	Really?	
G:	Yeah, I'm a dab hand at it now [Laughs].	
G:	Labels is great. They're about 15 quid.	
RMB:	Oh for the laminating?	
G:	Yeah, and you're always thinking of new things all the time, like, you know what's the best way I could have the schedule for him? Like, do I put another line beside it with ticks. I did that once before, putting the ticks beside, and I	Parent is always thinking of new ideas e.g. what's the best way I could have the schedule for the child? Parent asks questions to himself or herself before designing a visual for their child.

	found it just too messy. So now it's just one line with the pics on it, and then I have say em ... like a circle with the line going through, like not available? So say like, if he wants his time playing something ... and it's like, not available, the thing, and he understands that, and he doesn't like that. That's the not available sign yeah. That goes on top of it like, just with a bit of blue tack on top of it. Yeah, but yeah, it's grand, yeah.	Trial and error of what might work for the child.
RMB:	So really, you're, like your skills have really improved?	
G:	Have improved yeah, an awful lot, yeah. And your ideas as well, are kind of improving as well, yeah. Thinking of new things all the time.	Parent's skills have improved as well as ideas. Thinking of new things all the time.
RMB:	Yeah, so it's like once you figure out how, how they work I guess ..., you can think of creative ways ...	
G:	How can I improve that, yeah.	Parent is thinking of how they can improve on what they have made.
RMB:	Like, I think you were saying Sara, you know, using making it more interactive with the kids maybe, you know ..., I'm sure you use their interests as well in the visuals, as motivators maybe?	
G:	Yeah. Sponge Bob and stickers and things like that, yeah. Decorate it up so it's not just plain looking.	Parent uses child's interests when making up the visuals e.g. favorite cartoon characters.
G:	And If I do something from beginning to end, and then just introduce it to Tom, he has less interest. I sit ... and he does it with me, and he colours and he makes a choice, you know, ... say if I don't give him the whole thing, I'd say ok would you like an orange one, or a brown one, you know, and he chooses. I think he'll say orange, and he colours it in orange. He feels like he's had a part of it.	Child is more interested in visual if they have been involved in doing it or in taking part in the decision making process when parent is making it. Visuals encourage the child to make a choice.
RMB:	Very good.	

G:	And then everyone that comes gets a 'come here and have a look at this, what I created'.	Child feels proud of what they have created and shares what they have achieved with others with enthusiasm.
G:	Yeah.	
G:	You know, it's all about me, you know. [Laughter]. Oh look guys, look guys I have great news, come on I'll show you. You know. And if I do this, I'll get this. You know, so he's more ... about what he's creating everything.	
G:	It gives him something to talk about.	The visual the child has created gives him something to talk about.
G:	Instead of me just sticking something up, it's more like ...	
G:	It's not very good to have a few kid together, but the ...	
G:	Well the scrapbook is kind of what we done and that, they were saying in school, we ask him what he's done the weekend. He had nothing to say. So we'd send in the scrapbook and it would just be a picture of him in the park with his brother ... or, if we went to the circus, there'd be photographs from the circus. You seen the clowns, yeah, clown. Things like that. So the scrapbook was a good idea that ... it actually gave him something to talk about. Trying to get two-way communication, rather than just saying I like, or I want.	Scrapbook is used to encourage verbal language. Encourages the child to talk about what they have done over the weekend as opposed to just asking the child. Photographs help prompt the child.
RMB:	So it expands his communication skills and to be able to share that experience with other people.	Scrapbook gave the child something to talk about, like an activity or a location he'd been – provided an opportunity for 2-way communication. Other people were able to understand what the child had done.
G:	To show what he done yeah, absolutely. To engage in an activity he enjoyed, or somewhere he'd been.	
RMB:	Yeah, so Tony, how do you feel about using visuals with your child?	
G:	I don't have a problem using them. I would certainly recommend them. I ...	Parent has no issues using visuals now. Would recommend them.

kind of wish I got into it quicker ... and wasn't as head, I kind of know why I didn't want to but ... that was my thing [Laughs]. It wasn't anything with PECS, it was just a crazy idea I had myself so ... em, ... yeah, I should have used them earlier. And again like today, I have gotten a few ideas here that I will be printing up some at the weekend there, the hands and lollipops, and ...

Wishes they were more receptive to using them earlier. At first, was hesitant.

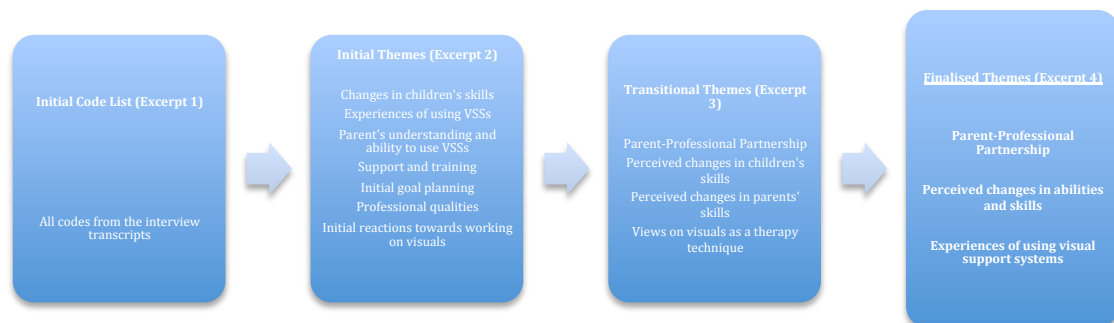
Group interview has given parent some ideas.

APPENDIX 16

CODE LIST

Example of Theme Development

The identified, finalised themes are presented in the diagram below. Information on how these themes developed through analysis is also displayed. Excerpt 1 provides a sample of the code list derived from the participant transcripts. Excerpts 2, 3, and 4 provide samples of the thematic groupings at different stages during the analysis.



Excerpt 1: Code List

A sample from the initial code list originating from the interview transcripts is presented below. Data was listed alphabetically, with duplicated codes from the same participants removed in order to aid the grouping of codes later on.

P1
P2
P3
G (Group participants)
P5
P6
P7

- A verbal message can be too quick
- Accepting diagnosis needed to come first before understanding visuals
- Advice from other parents is more beneficial then professionals saying use visuals

- Afraid to put too much info in social stories - afraid of doing the wrong thing
- After diagnosis, support was delayed – no access to courses therefore research done by herself
- All totally new – introduced to them before they knew what it was totally about
- Allows you to set up opportunities for more practices e.g. breaking cookie up into many pieces
- Always work in progress
- As child gets older visuals stick out more
- At first didn't want to use them – personal issues
- At first visuals took time to make as parent needed to get right pictures, printing them, laminating them – can take hours/weeks, finding where to buy Velcro
- At first was resistant (felt was too regimented) but once started using and saw improvement decided to go with it
- Behaviour improved
- Big book is bulky to carry, can be lost easily
- Breaking down what might be a simple task like getting dressed might actually require a lot of pictures
- But when made one that worked, kept using
- Can be an eye sore having pictures around house
- Can be costly
- Can be hard to gauge child's level of understanding with pictures – is he discriminating – especially if it doesn't bother child – Is he understanding where we are going? Or is he lazy/laid back?
- Can be impractical around the house – sticking up lots of pictures
- Can break down a task into very small steps
- Can prepare for big events but sometimes things happen last minute
- Can't be used when there is an unplanned event like a fire engine sound
- Carrying all of them can be impractical though sometimes
- Changes happen unexpectedly
- Child commenting more
- Child demonstrating improved cognition
- Child demonstrating improved confidence
- Child demonstrating less frustration
- Child enjoys looking at pictures
- Child expressing more needs
- Child followed visuals to a tee so parent felt needed to be adapted
- Child is visual
- Child is visual
- Child knows what to do during routines
- Child less anxious
- Child likes using visuals
- Child might decide a picture means something to them
- Child understands events that may have not before eg. Birthday
- Child understands expectations

- Child understands visuals
- Child using more language
- Child's understanding and expression improved
- Children began to understand changes in routine/events
- Children began to understand first/next commands
- Children can be very literal – so HAS to be like picture – disadvantage of using them like when out and about – important that professionals tell you that its black and white for children with autism not grey
- Children notice details in pictures that might be different to what they are thinking
- Children very visual so uses a strength of theirs
- Clinic being all visual is helpful eg pictures of staff
- Confusion as to how much detail to put in
- Constantly have to monitor PECS book
- Count down helps break down a task
- Course provided extra support as opposed to just watching other professionals
- Dealing with unexpected change can be hard to show with pictures – takes too much time and effort
- Delayed and limited services
- Didn't fully understand why you would need them
- Didn't know how to approach it with no support
- Didn't know if was doing it right
- Didn't know what to think when first saw them
- Didn't want child to be too dependent – and parent also to have to rely on same thing everyday
- Different pictures can represent different objects
- Difficult to use PECS when child doesn't have many interests
- Doesn't use them as often now that child can talk
- Doesn't use them often now that child is ok with change
- Don't have a problem using them
- Don't mind because its helping – you get used to it, another activity, don't need it that often
- Don't mind using pictures if it helps child
- Don't think visuals could do a lot
- Don't want child to stick out as being too different
- Don't want him to get too reliant
- Don't want to set up an expectation for the child if they are not followed through by professionals
- Door with handle door without
- Drawn into visuals straight away
- E.g. chase fast chase slow chase?
- Early bird helped to see different children, different situations, different schedules
- Easy to use as is simple and also shares moment with child when reading it – like reading a book
- Effective
- Encourages child to think for himself

- Experienced home tutor introduced them at home
- Family members and other people can communicate with the child
- Feel more confident putting them together following training
- Find VSSs very good
- Fine line between using them to prepare himself and not having a meltdown if things don't go according to plan
- Follow up courses are helpful
- Found visuals help
- Found visuals helpful
- Frequent training is helpful – you don't always know it all
- Frustrating when visuals don't work instantly – especially if you have attempted to make them and then they need to be adapted
- Gap around services – feel vulnerable
- Gets more tricky as child gets older – other children begin to realise
- Gives child space to process what has been said
- Going to new school – specific events
- Got tips from focus group – talking to other parents
- Great to encourage child to use with different family members
- Hadn't heard about them before
- Hadn't seen them before
- Happy to go with professionals' recommendations – anything that would help
- Happy to keep images on parents just in case they are needed once parents got used to the idea of having to do so
- Hard to plan for all events
- Hard to remember to bring PECS book each time
- Harder if extended family don't take on board visuals
- Has to be used consistently
- Having photographs of brands can be a disadvantage if they change packaging
- Having them displayed helps – child can look at it when they want
- Helped eating snack at school and new foods at home
- Helped starting conversations
- Helpful for daily routines e.g. toileting
- Helpful for making choices of preferred activities
- Helpful if other professionals are on board with you
- Helpful to hear other parents' stories
- Helpful to read not too early or too late
- Helpful to take any information from professionals
- Helpful when professional gives them a guide of a story to adapt
- Helps child to understand that parents understand what they mean/want
- Helps child understand changes in routine
- Helps child understand what is happening next
- Helps express feelings
- Helps parent ask child less questions and more natural conversation
- Helps reduce child's anxiety
- Helps to remind child of what next step is

- Helps with social skills – using correct words, tone etc
- Hesitant to start as you could do more harm than good
- High or low tech works just the same – depends on your own abilities
- High tech allows for things like bigger writing promoting reading skills
- High tech visuals have disadvantages
- If child is having a meltdown getting visuals out at that stage isn't always very helpful
- If it was practical then it was more used
- If you made a promise with a visual and that changes, it can be hard for child with autism to deal with and for parent to explain
- Including visuals with everyone in house doesn't make child feel excluded or put too much attention on one child
- Increased understanding of commands
- Information provided but no support
- Internet can be overwhelming with information – information can be academic
- Internet provides lots of pictures – can be negative or positive
- Introduced to pictures following training
- Involving child in creating visuals helps – child can then share/talk about what they have made with other family members
- It is easier to use if everyone takes them on board
- Its important that if you introduce them that other people take them on board too
- Just because pictures are presented doesn't mean child will always go for them. Parent needs to teach them first
- Knows more about it as time went on
- Laminator can break
- Learned at their own pace with support of professionals
- Learning as you go along
- Learning with other parents is more beneficial
- Less behaviours observed
- Less whinging
- Liked home work on visuals
- Liked written information on visuals
- Limited for expressing feelings
- Little help provided
- Lots of information out there
- Makes an event more tangible – puts a beginning middle and end
- Making them available to child to use when ever they want
- Making visuals can be time-consuming
- Making visuals requires lots of planning
- Managing hair cutting better
- Many pictures are required
- More needed to help parents feel more empowered to work with their child
- Most classrooms are visual anyways and you wouldn't realise with a normal child
- Most powerful was to see how effective they can be after tried

- Most research was done by parent
- Needs to be consistency in pictures between home and school
- Needs to be individualised so cant just go buy any pictures sometimes
- Never had a need to go and look up information – too much information out there
- Never seen them before professional started using them
- Not always possible to show pictures
- Not mainstream knowledge to use visuals – only after you are told
- Not used if not needed on a daily basis
- Once child could read, pictures weren't as important
- Once child was less frustrated, parents were less frustrated
- Once not needed were removed
- Once they ask with pictures you cant refuse
- Once they saw visuals worked, they were more open to using them
- Once they worked, parent was more confident, and wanted to learn more
- One parent found session useful for getting advice from others or professional
- Only after diagnosis were we told of visuals
- Other children in house can feel excluded if its only for child with autism
- Parent cuts up and laminates
- Parent gathers information of steps involved
- Parent happy with professional doing it
- Parent has folder of stories they use when needed
- Parent has more understanding of how to make up visuals
- Parent has no issues using visuals with child
- Parent is confident they work
- Parent is more technological than they realise – confidence?
- Parent knows when child really needs visuals or whether a verbal message is enough
- Parent loves using them – helps that child likes them as well
- Parent organised them in a folder – child still likes looking at stories even though might not need them
- Parent printed and laminated pictures herself also
- Parent saw how the visuals were used at school
- Parent understood what visuals where as was familiar to them prior to clinic sessions – no problem understanding them as was exposed to them before
- Parent using them more now than the past after she has seen changes in her child
- Parent was happy to work on visuals
- Parent was provided with written information and verbal information on how to make visuals
- Parent would like more information on social stories
- Parents are coming up with new ways of how things might work for their child – more confident, trial and error works
- Parents are not professionals

- Parents became better at producing more high quality pictures – re sizing, laminating
- Parents come up with new creative ideas after they introduce visuals
- Parents desperate for information
- Parents felt they learned from sharing ideas in the focus group
- Parents had less power to write their own – teachers wrote them
- Parents have thought of creative ways on their own to use visuals – teaching stop/go, increasing language
- Parents learned new skills as they went along
- Parents make own visuals off internet or phone or specific apps, Google images, buy from shops – print and laminate
- Parents were advised to use generic pictures
- Parents were giving each other advice during interview
- Parents were told to get on with it
- Parents worked with professionals
- Pc and laminator
- PECS book can be bulky to bring to places
- PECS book needs to be managed and updated regularly
- PECS is limited
- PECS is limited to how much you can express yourself
- PECS requires a lot of planning
- PECS training requires use of ‘goodies’
- Phone camera useful
- Physically putting images together may not be practical – practical element
- Pictures can be flimsy and want to eat them
- Pictures can be limited in amount of words child needs to express
- Pictures can tend to fall apart as they are used often
- Pictures limited in what they can express e.g. juice and flavour of juice
- Pictures started in school
- Planning around visuals can be exhausting
- Planning Skills improved
- Preparing really helps for bit situations
- Professional is very good at it – overpowering? empowerment? Professional is better on computer – parent never tried because professional did it – but parent inputted by taking photographs
- Professionals appeared knowledgeable
- Professionals explained them quickly
- Professionals gave parents pictures
- Professionals gave useful advice that was specific to child’s needs
- Professionals guided parents
- Professionals have experience and that’s needed long term
- Professionals introduced visuals
- Professionals not always on board with parents goals
- Professionals still do some visuals for parents – find that very supportive – but feel confident to do their own
- Professionals told parents of pictures,
- Professionals told parents to use visuals

- Professionals used them in the clinics – that's how parents initially exposed
- Rather speak to child then use pictures
- Realising as you go along what they are and that they work
- Requires a lot of planning and thinking
- Requires technology dropping pictures in a story – parent doesn't know how to do – but recognises you don't have to be very technological to do it – u can just paste pictures – but likes better how finished product looks with higher technology – nice to keep them in a folder
- Satisfied with the support
- Saw visuals in the clinic
- Schedules not always needed on a daily basis
- School encouraged parent to use pictures
- School explained to parent how pictures could be used
- Showing how to use them and examples helped with parents' understanding
- Sibling was also using them with brother
- Siblings usually want to be involved too
- Social stories cant be introduced if child has no understanding
- Social stories training didn't always help parents to understand what they should be doing
- Social stories training wasn't applied to parents' issues with children and was somewhat general
- Some are generic to prevent that literal understanding – can really affect child
- Some pictures can be abstract so you have to select based on your child's understanding
- Some prefer using photographs as it makes it more personal
- Some saw it as just an evolving idea from a schedule to a timetable
- Sometimes it doesn't always work
- Sometimes its hard to predict what is going to happen in a situation so harder to write a story if parent themselves doesn't know what's happening
- Sometimes pictures go missing
- Sometimes visuals aren't used in mainstream because teacher doesn't follow through
- Sometimes visuals can take time for child to learn something new
- Spend ages doing pictures and then might not be right for child
- Starting alone would have been very daunting
- Still a lot of mind reading to be done
- Still seen as something that is needed or not?
- Stopped using them because didn't think they worked
- Support has to be for everyone in house not only child with autism
- Support was poor – told about it but parent had to look it up
- Symbols aren't used universally
- Takes a bit of getting your head around using it in the community
- Teacher would print off pictures
- Teaching visuals can require 2 people

- Team have been very supportive
- Technology requires time
- The more they understood how they worked the more they could apply it to their child's needs
- They don't always see what you see in the pictures – recognising this has helped parents tailor make their pictures
- Time consuming especially with lots of little pictures
- Token board for positive behaviours
- Too many pictures of strawberries on internet
- Training also helpful to encourage other parents to use it
- Training didn't always apply to parents' situation
- Training helped
- Training provided
- Training was useful. You might need to go back where you started.
- Travelling with pictures can be cumbersome
- Trial and error for learning how to use visuals
- Trying to get free ones together is time consuming and requires planning
- Trying to get the balance right between the child being comfortable and doing thinking for himself
- Uncertain as to whether child will need them forever
- Understanding of where they are going improved
- Used mostly when needed such as big change coming
- Using child's interests can make it more appealing for child e.g. Favourite cartoon character
- Using pictures can require more than one person especially for training
- Using sweets to motivate child
- Using the same picture in different environments can be problematic
- Using them to prepare for an event is helpful even though child may have experienced experience before because you never know how they are going to be that day
- Using visuals can feel like you are lowering your child's expectations especially if their speech is improving
- Using visuals in front of siblings makes the child stick out as different – and parents don't always want to explain autism yet
- Velcro can be hard to find
- Velcro can destroy your clothes
- Video examples from other parents were more useful
- Visual pictures aren't always universal
- Visuals 'solidified' words in child's mind
- Visuals are more easily understood than verbal instructions
- Visuals are particularly useful for big changes
- Visuals aren't always enough to express all needs
- Visuals aren't always understood by everyone
- Visuals aren't things you just think up yourself even though you see them all around you.
- Visuals calmed the child
- Visuals can be bulky to carry

- Visuals can be expensive to just buy
- Visuals can be interpreted differently by different children
- Visuals can be rigid
- Visuals can be understood by most people
- Visuals can be used by all family members
- Visuals can be used even if child has no intellectual disability – stigma?
- Visuals can't replace language
- Visuals don't always work – if child is tired certain behaviours are inevitable
- Visuals help child verbalise not only wants but also experiences
- Visuals help other areas not only speech
- Visuals helped child communicate needs – whether has speech or not
- Visuals helped parents reduce their language and remain calmer in tougher situations
- Visuals helped reduce anxiety
- Visuals helped siblings and other family members
- Visuals kept it strict
- Visuals make explaining an instruction easier
- Visuals promote reading skills
- Visuals removed, reduced, and/or adapted based on child's needs/ growing skills
- Visuals take planning – can't just type it up – u have to go to places to take photographs especially for specific ones eg hospital appointment
- Visuals used for teaching academic skills
- Visuals used on wall in home just as a reminder – but someone wouldn't feel comfortable removing them just yet
- Visuals work when there is a non-preferred activity followed by a preferred one
- Watching other professionals use social stories helped
- Were used more when child had no language
- What do parents think visuals are?
- When it was suggested parents didn't always understand what professionals meant
- When visuals don't work you are a bit like...?
- Wish I used them earlier
- Wish that professionals would sometimes offer another alternative other than visuals
- Words under pictures help others identify pictures if they are not clear
- Words under pictures help promote reading
- Worried child will be dependent on visuals if used too much
- Would be lost without support
- Would like to think that one day child won't need them – wouldn't require them as much
- Would recommend them
- You can all understand pictures as opposed to sign language
- You can never say you know everything – never finished learning
- You can't get complacent, you are learning all along
- You can't have a visual for every single thing

- You cant have stories for every single little thing – child was getting used to this idea – schedule is helpful and can be quick
- You don't think that you are going to use them to e.g. dress your child
- You just get on with it
- You learn as you go along
- You learn as you go on
- You may need a lot of pictures
- You need desirable food items and most are poor eaters
- You need to be a high tech person
- You need to remember to bring your visuals with you
- You wish there was another cure – may be you are not being told about

Excerpt 2: Initial Themes

P1

P2

P3

G (Group participants)

P5

P6

P7

Changes in children's skills

- Behaviour improved
- Child knows what to do during routines
- Child understands events that may have not before e.g. Birthday
- Child understands expectations
- Child's understanding and expression improved
- Fewer frustrations
- Going to new school – specific events
- Helped eating snack at school and new foods at home
- Helped starting conversations
- Helpful for daily routines eg toileting
- Helpful for making choices of preferred activities
- Improved cognitive processes
- Improved confidence
- Increased understanding of commands
- Less anxiety
- Less behaviour
- Less whinging
- Managing hair cutting better
- Now commenting
- Now expressing needs

- Now uses language
- Token board for positive behaviours helpful
- Understanding change in routine/event improved
- Understanding of first/then improved
- Understanding of where they are going improved

Experiences of using VSSs:

Positives of VSSs

- A verbal message can be too quick
- Available for child to use when ever they want
- Can break down a task into very small steps
- Child enjoys looking at pictures
- Child is visual
- Child is visual
- Child likes using visuals
- Children very visual so uses a strength of theirs
- Count down helps break down a task
- Drawn into visuals straight away
- Easy to use as is simple and also shares moment with child when reading it – like reading a book
- Effective
- Encourages child to think for himself
- Family members and other people can communicate with the child
- Found visuals helpful
- Gives child space to process what has been said
- Helps child to understand that parent understands
- Helps child understand changes in routine
- Helps child understand what is happening next
- Helps express feelings
- Helps parent ask child less questions and more natural conversation
- Helps reduce child's anxiety
- Helps to remind child of what next step is
- Helps with social skills – using correct words, tone etc.
- Improved understanding
- Including visuals with everyone in house doesn't make child feel excluded or put too much attention on one child
- Increased child's happiness
- Less upset
- Makes an event more tangible – puts a beginning middle and end
- Most people understand them
- Once child was less frustrated, parents were less frustrated
- Planning Skills improved
- Positives outweigh the negatives
- Preparing really helps for big situations
- Solidified words in child's mind

- Using child's interests can make it more appealing for child e.g. Favourite cartoon character
- Using them to prepare for an event is helpful even though child may have experienced experience before because you never know how they are going to be that day
- Visuals are more easily understood than verbal instructions
- Visuals are particularly useful for big changes
- Visuals can be used by all family members
- Visuals can be used even if child has no intellectual disability
- Visuals can be used for teaching academic skills
- Visuals don't necessarily make a family look different
- Visuals help a child 'see' what's happening
- Visuals help child verbalise not only wants but also experiences
- Visuals help keep routine and structure the home
- Visuals help other areas not only speech
- Visuals help the child
- Visuals helped child communicate needs – whether has speech or not
- Visuals helped parents reduce their language and remain calmer in tougher situations
- Visuals helped siblings and other family members
- Visuals make explaining an instruction easier
- Visuals reduce anxiety
- Were used more when child had no language
- Word under picture helps with reading skills
- Words under pictures help others identify pictures if they are not clear
- Words under pictures help promote reading
- You can all understand pictures as opposed to sign language

Negatives of VSSs

- As child gets older visuals stick out more
- At first visuals took time to make as parent needed to get right pictures, printing them, laminating them – can take hours/weeks, finding where to buy Velcro
- Big book is bulky to carry, can be lost easily
- Breaking down what might be a simple task like getting dressed might actually require a lot of pictures
- Bulky to carry
- Can be an eye sore having pictures around house
- Can be costly
- Can be hard to gauge child's level of understanding with pictures – is he discriminating – especially if it doesn't bother child – Is he understanding where we are going? Or is he lazy/laid back?
- Can be impractical around the house – sticking up lots of pictures
- Can prepare for big events but sometimes things happen last minute
- Can't be used when there is an unplanned event like a fire engine sound
- Carrying all of them can be impractical though sometimes

- Changes happen unexpectedly
- Child followed visuals to a tee so parent felt needed to be adapted
- Child may want to eat them
- Child might decide a picture means something to them
- Child might interpret picture differently
- Children can be very literal – so HAS to be like picture – disadvantage of using them like when out and about – important that professionals tell you that its black and white for children with autism not grey
- Children notice details in pictures that might be different to what they are thinking
- Constantly have to monitor PECS book
- Dealing with unexpected change can be hard to show with pictures – takes too much time and effort
- Didn't want child to be too dependent – and parent also to have to rely on same thing everyday
- Different pictures can represent same object
- Difficult to use PECS when child doesn't have many interests
- Difficulty using same picture in different environments
- Doesn't use them as often now that child can talk
- Doesn't use them often now that child is ok with change
- Don't want child to stick out as being too different
- Don't want him to get too reliant
- Hard to plan for all events
- Hard to remember to bring PECS book each time
- Harder if extended family don't take on board visuals
- Has to be used consistently
- Having photographs of brands can be a disadvantage if they change packaging
- If child is having a meltdown getting visuals out at that stage isn't always very helpful
- If you made a promise with a visual and that changes, it can be hard for child with autism to deal with and for parent to explain
- It isn't enough to express all needs
- Just because pictures are presented doesn't mean child will always go for them. Parent needs to teach them first
- Laminator can break
- Limited for expressing feelings
- Lots of pictures on internet
- Need a lot of pictures
- Needs to be consistency in pictures between home and school
- Needs to be individualised so cant just go buy any pictures sometimes
- Not always possible to show pictures
- Once they ask with pictures you cant refuse
- Other children in house can feel excluded if its only for child with autism
- PECS book can be bulky to bring to places
- PECS book needs to be managed and updated regularly
- PECS is limited

- PECS is limited to how much you can express yourself
- PECS requires a lot of planning
- Physically putting images together may not be practical – practical element
- Pictures aren't always easy to understand
- Pictures aren't always universal
- Pictures can be flimsy
- Pictures can be limited in amount of words child needs to express
- Pictures can tend to fall apart as they are used often
- Pictures limited in what they can express e.g. juice and flavour of juice
- Planning around visuals can be exhausting
- Putting them together takes time
- Rather speak to child then use pictures
- Requires a lot of planning
- Requires a lot of planning and thinking
- Requires technology dropping pictures in a story – parent doesn't know how to do – but recognises you don't have to be very technological to do it – u can just paste pictures – but likes better how finished product looks with higher technology – nice to keep them in a folder
- Schedules not always needed on a daily basis
- Some pictures can be abstract so you have to select based on your child's understanding
- Sometimes it doesn't always work
- Sometimes its hard to predict what is going to happen in a situation so harder to write a story if parent themselves doesn't know what's happening
- Sometimes pictures go missing
- Sometimes visuals can take time for child to learn something new
- Spend ages doing pictures and then might not be right for child
- Still a lot of mind reading to be done
- Symbols aren't used universally
- Takes a bit of getting your head around using it in the community
- Technology requires time
- Time consuming
- Time consuming especially with lots of little pictures
- Too many pictures of 'strawberries' on internet
- Travelling with pictures can be cumbersome
- Trying to get free ones together is time consuming and requires planning
- Trying to get the balance right between the child being comfortable and doing thinking for himself
- Uncertain as to whether child will need them forever
- Uses goodies – can be a negative
- Using pictures can require more than one person especially for training
- Using sweets to motivate child can be a disadvantage
- Using visuals can feel like you are lowering your child's expectations especially if their speech is improving

- Using visuals in front of siblings makes the child stick out as different – and parents don't always want to explain autism yet
- Velcro can be hard to find
- Velcro can destroy your clothes
- Visuals can be expensive to just buy
- Visuals can be rigid
- Visuals can't replace language
- Visuals don't always work – if child is tired certain behaviours are inevitable
- Visuals kept it strict
- Visuals take planning – can't just type it up – u have to go to places to take photographs especially for specific ones eg hospital appointment
- When visuals don't work you are a bit like...?
- You can't have a visual for every single thing
- You can't have stories for every single little thing – child was getting used to this idea – schedule is helpful and can be quick
- You may need a lot of pictures
- You need desirable food items and most are poor eaters
- You need to be a high tech person
- You need to remember to bring your visuals with you
- You need two people to teach them

Parents' understanding and ability to use visuals

- Accepting diagnosis needed to come first before understanding visuals
- Afraid to put too much info in social stories – afraid of doing the wrong thing
- Allows you to set up opportunities for more practices e.g. breaking cookie up into many pieces
- Always work in progress
- Happy to continue to use visuals for the rest of the child's life if it helps him.
- Mother is happier and more confident following the support she has received.
- Mother thinks the reason some people choose to use visuals is because they can't accept their child's diagnosis or are unfamiliar with them
- Mother would do anything to help her child
- Obtaining the information on what they are and giving visuals a chance is what helped mum to use them
- Parent cuts up and laminates
- Parent gathers information of steps involved
- Parent happy with professional doing it
- Parent has folder of stories they use when needed
- Parent has more understanding of how to make up visuals
- Parent is confident they work
- Parent is more technological than they realise – confidence?

- Parent knows when child really needs visuals or whether a verbal message is enough
- Parent loves using them – helps that child likes them as well
- Parent organised them in a folder – child still likes looking at stories even though might not need them
- Parents are coming up with new ways of how things might work for their child – more confident, trial and error works
- Parents became better at producing more high quality pictures – re sizing, laminating
- Parents come up with new creative ideas after they introduce visuals
- Parents felt they learned from sharing ideas in the focus group
- Parents have thought of creative ways on their own to use visuals – teaching stop/go, increasing language
- Parents learned as they went along
- Parents make own visuals off internet or phone or specific apps, Google images, buy from shops – print and laminate
- The more they understood how they worked they more they could apply it to their child's needs
- They don't always see what you see in the pictures – recognising this has helped parents tailor make their pictures
- Using pictures was a trial and error process
- Visuals always worked for her child. Practice and repetition helped child grasp the concept
- You can never say you know everything – never finished learning
- You can't get complacent, you are learning all along

Support and Training:

Satisfaction with support and training provided

- Advice from other parents is more beneficial than professionals saying use visuals
- Clinic being all visual is helpful e.g. pictures of staff
- Course provided extra support as opposed to just watching other professionals
- Early bird helped to see different children, different situations, different schedules
- Follow up courses are helpful
- Frequent training is helpful – you don't always know it all
- Good support in school he was at
- Helpful to take any information from professionals
- Helpful when professional gives them a guide of a story to adapt
- Homework helpful
- Information on visuals was helpful
- Learning with other parents is more beneficial
- Lots of staff using pictures in the classroom setting
- Meetings with school staff helped parent understand visuals
- Mum saw how they worked in the classroom

- Never had a need to go and look up information – too much information out there
- Satisfied with the support
- School offered a lot of information
- Showing how to use them and examples helped with parents' understanding
- Starting alone would have been very daunting
- Support was specific to the child's needs
- Training also helpful to encourage other parents to use it
- Training helped
- Training was provided
- Training was useful. You might need to go back where you started.
- Verbal support from school helped understand visuals
- Video examples from other parents were more useful
- Watching other professionals use social stories helped
- Would be lost without support
- Written information provided and helpful

Dissatisfaction with support and training provided

- After diagnosis, support was delayed – no access to courses therefore research done by herself
- Delayed and limited services
- Didn't know how to approach it with no support
- Didn't know if was doing it right
- Don't want to set up an expectation for the child if they are not followed through by professionals
- Helpful if other professionals are on board with you
- Information provided but no support
- Little help provided
- More support needed to help parents feel more empowered to work with their child
- Most research was done by parent
- Parents are not professionals
- Professionals not always on board with parents' goals
- Sometimes visuals aren't used in mainstream because teacher doesn't follow through
- Support has to be for everyone in house not only child with autism
- Support was poor – told about it but parent had to look it up
- Training didn't always apply to parents' situation

Initial goal planning

- All totally new – introduced to them before they knew what it was totally about
- Didn't fully understand why you would need them
- Experienced home tutor introduced them at home
- Hadn't heard about them before
- Hadn't seen them before

- Happy to go with professionals' recommendations – anything that would help
- Mum had been introduced to visuals through community early intervention services but she didn't quite understand what they were
- Mum took the initiative to try to understand more what they were before her child started school because they were also using visuals in that placement
- Never seen them before professional started using them
- Not mainstream knowledge to use visuals – only after you are told
- Only after diagnosis were we told of visuals
- Parent understood what visuals were as was familiar to them prior to clinic sessions – no problem understanding them as was exposed to them before
- Parents were told to get on with it
- Professionals decided what goals to work on
- Professionals gave pictures to parents
- Professionals introduced visuals
- Professionals told parents of pictures
- Professionals told parents to use visuals
- School staff first properly introduced mum to visuals

Professionals' Qualities

- Professionals appeared knowledgeable
- Professionals explained them quickly
- Professionals gave useful advice that was specific to child's needs
- Professionals guided parents
- Professionals used them in the clinics – that's how parents initially exposed

Initial reactions towards working on visuals

- At first didn't want to use them – personal issues
- At first was resistant (felt was too regimented) but once started using and saw improvement decided to go with it
- Didn't know what to think when first saw them
- Hesitant to start as you could do more harm than good
- Parents desperate for information
- Parents worked with professionals
- Visuals aren't things you just think up yourself even though you see them all around you.
- When it was suggested parents didn't always understand what professionals meant
- You don't think that you are going to use them to e.g. dress your child
- You just get on with it

Excerpt 3: Transitional Themes

P1

P2

P3

G (Group participants)

P5

P6

P7

Parent-Professional Partnership:

Goal Planning

- All totally new – introduced to them before they knew what it was totally about
- At first didn't want to use them – personal issues
- At first was resistant (felt was too regimented) but once started using and saw improvement decided to go with it
- Didn't fully understand why you would need them
- Didn't know what to think when first saw them
- Experienced home tutor introduced them at home
- Hadn't heard about them before
- Hadn't seen them before
- Happy to go with professionals' recommendations – anything that would help
- Hesitant to start as you could do more harm than good
- Mum had been introduced to visuals through community early intervention services but she didn't quite understand what they were
- Mum took the initiative to try to understand more what they were before her child started school because they were also using visuals in that placement
- Never seen them before professional started using them
- Not mainstream knowledge to use visuals – only after you are told
- Only after diagnosis were we told of visuals
- Parent understood what visuals were as was familiar to them prior to clinic sessions – no problem understanding them as was exposed to them before
- Parents desperate for information
- Parents were told to get on with it
- Parents worked with professionals
- Professionals decided what goals to work on
- Professionals gave pictures to parents
- Professionals introduced visuals
- Professionals told parents of pictures
- Professionals told parents to use visuals

- School staff first properly introduced mum to visuals
- Visuals aren't things you just think up yourself even though you see them all around you.
- When it was suggested parents didn't always understand what professionals meant
- You don't think that you are going to use them to e.g. dress your child
- You just get on with it

Professionals' Qualities

- Helpful if other professionals are on board with you
- Helpful when professional gives them a guide of a story to adapt
- Never had a need to go and look up information – too much information out there
- Professionals appeared knowledgeable
- Professionals explained them quickly
- Professionals gave useful advice that was specific to child's needs
- Professionals guided parents
- Professionals used them in the clinics – that's how parents initially exposed
- Showing how to use them and examples helped with parents' understanding
- Sometimes visuals aren't used in mainstream because teacher doesn't follow through
- Support was specific to the child's needs
- Verbal support from school helped understand visuals
- Watching other professionals use social stories helped

Service Provision

- After diagnosis, support was delayed – no access to courses therefore research done by herself
- Clinic being all visual is helpful e.g. pictures of staff
- Delayed and limited services
- Didn't know how to approach it with no support
- Didn't know if was doing it right
- Don't want to set up an expectation for the child if they are not followed through by professionals
- Good support in school he was at
- Homework helpful
- Information on visuals was helpful
- Information provided but no support
- Little help provided
- Lots of staff using pictures in the classroom setting
- Meetings with school staff helped parent understand visuals
- More support needed to help parents feel more empowered to work with their child
- Most research was done by parent

- Mum saw how they worked in the classroom
- Parents are not professionals
- Professionals not always on board with parents' goals
- Satisfied with the support
- School offered a lot of information
- Starting alone would have been very daunting
- Support has to be for everyone in house not only child with autism
- Support was poor – told about it but parent had to look it up
- Would be lost without support
- Written information provided and helpful

Parent Training

- Advice from other parents is more beneficial than professionals saying use visuals
- Course provided extra support as opposed to just watching other professionals
- Early bird helped to see different children, different situations, different schedules
- Follow up courses are helpful
- Frequent training is helpful – you don't always know it all
- Helpful to take any information from professionals
- Learning with other parents is more beneficial
- Training also helpful to encourage other parents to use it
- Training didn't always apply to parents' situation
- Training helped
- Training was provided
- Training was useful. You might need to go back where you started.
- Video examples from other parents were more useful

Perceived changes in children's skills

Behaviour

- Behaviour improved
- Fewer frustrations
- Less anxiety
- Less behaviour
- Less whinging
- Managing hair cutting better
- Token board for positive behaviours helpful

Communication

- Child knows what to do during routines
- Child understands expectations

- Child's understanding and expression improved
- Helped starting conversations
- Helpful for daily routines e.g. toileting
- Helpful for making choices of preferred activities
- Increased understanding of commands
- Now commenting
- Now expressing needs
- Now uses language
- Understanding change in routine/event improved
- Understanding of first/then improved
- Understanding of where they are going improved

Other

- Child understands events that may have not before e.g. Birthday
- Going to new school – specific events
- Helped eating snack at school and new foods at home
- Improved cognitive processes
- Improved confidence

Perceived changes in parents' skills

Confidence

- Afraid to put too much info in social stories – afraid of doing the wrong thing
- Happy to continue to use visuals for the rest of the child's life if it helps him.
- Mother is happier and more confident following the support she has received.
- Mother thinks the reason some people choose not to use visuals is because they can't accept their child's diagnosis or are unfamiliar with them
- Mother would do anything to help her child
- Parent is confident they work
- Parent is more technological than they realise – confidence?
- Visuals always worked for her child. Practice and repetition helped child grasp the concept

Understanding

- Accepting diagnosis needed to come first before understanding visuals
- Always work in progress
- Parent has more understanding of how to make up visuals
- Parent knows when child really needs visuals or whether a verbal message is enough
- Parents felt they learned from sharing ideas in the focus group

- The more they understood how they worked the more they could apply it to their child's needs
- You can never say you know everything – never finished learning
- You can't get complacent, you are learning all along

Creativity and craft skills

- Parent cuts up and laminates
- Parent gathers information of steps involved
- Parents are coming up with new ways of how things might work for their child – more confident, trial and error works
- Parents became better at producing more high quality pictures – re sizing, laminating
- Parents come up with new creative ideas after they introduce visuals
- Parents have thought of creative ways on their own to use visuals – teaching stop/go, increasing language
- They don't always see what you see in the pictures – recognising this has helped parents tailor make their pictures

Parenting skills

- Obtaining the information on what they are and giving visuals a chance, is what helped mum to use them
- Parent happy with professional doing it
- Parent has folder of stories they use when needed
- Parent loves using them – helps that child likes them as well

Ability

- Parent organised them in a folder – child still likes looking at stories even though might not need them
- Parents learned as they went along
- Parents make own visuals off internet or phone or specific apps, Google images, buy from shops – print and laminate
- Using pictures was a trial and error process

Views on visuals as a therapy technique

Time-consuming

- At first visuals took time to make as parent needed to get right pictures, printing them, laminating them – can take hours/weeks, finding where to buy Velcro
- Putting them together takes time
- Spend ages doing pictures and then might not be right for child
- Technology requires time
- Time consuming
- Time consuming especially with lots of little pictures

- Trying to get free ones together is time consuming and requires planning

Siblings

- Family members and other people can communicate with the child
- Including visuals with everyone in house doesn't make child feel excluded or put too much attention on one child
- Other children in house can feel excluded if its only for child with autism
- Using visuals in front of siblings makes the child stick out as different – and parents don't always want to explain autism yet
- Visuals can be used by all family members

Practicalities

- A verbal message can be too quick
- Allows you to set up opportunities for more practices e.g. breaking cookie up into many pieces
- As child gets older visuals stick out more
- Available for child to use when ever they want
- Big book is bulky to carry, can be lost easily
- Breaking down what might be a simple task like getting dressed might actually require a lot of pictures
- Bulky to carry
- Can be an eye sore having pictures around house
- Can be costly
- Can be hard to gauge child's level of understanding with pictures – is he discriminating – especially if it doesn't bother child – Is he understanding where we are going? Or is he lazy/laid back?
- Can be impractical around the house – sticking up lots of pictures
- Can break down a task into very small steps
- Can prepare for big events but sometimes things happen last minute
- Cant be used when there is an unplanned event like a fire engine sound
- Carrying all of them can be impractical though sometimes
- Changes happen unexpectedly
- Child enjoys looking at pictures
- Child followed visuals to a tee so parent felt needed to be adapted
- Child is visual
- Child is visual
- Child likes using visuals
- Child may want to eat them
- Child might decide a picture means something to them
- Child might interpret picture differently
- Children can be very literal – so HAS to be like picture – disadvantage of using them like when out and about – important that professionals tell you that its black and white for children with autism not grey

- Children notice details in pictures that might be different to what they are thinking
- Children very visual so uses a strength of theirs
- Constantly have to monitor PECS book
- Count down helps break down a task
- Dealing with unexpected change can be hard to show with pictures – takes too much time and effort
- Didn't want child to be too dependent – and parent also to have to rely on same thing everyday
- Different pictures can represent same object
- Difficult to use PECS when child doesn't have many interests
- Difficulty using same picture in different environments
- Doesn't use them as often now that child can talk
- Doesn't use them often now that child is ok with change
- Don't want child to stick out as being too different
- Don't want him to get too reliant
- Drawn into visuals straight away
- Easy to use as is simple and also shares moment with child when reading it – like reading a book
- Effective
- Encourages child to think for himself
- Found visuals helpful
- Gives child space to process what has been said
- Hard to plan for all events
- Hard to remember to bring PECS book each time
- Harder if extended family don't take on board visuals
- Has to be used consistently
- Having photographs of brands can be a disadvantage if they change packaging
- Helps child to understand that parent understands
- Helps child understand changes in routine
- Helps child understand what is happening next
- Helps express feelings
- Helps parent ask child less questions and more natural conversation
- Helps reduce child's anxiety
- Helps to remind child of what next step is
- Helps with social skills – using correct words, tone etc.
- If child is having a meltdown getting visuals out at that stage isn't always very helpful
- If you made a promise with a visual and that changes, it can be hard for child with autism to deal with and for parent to explain
- Improved understanding
- Increased child's happiness
- It isn't enough to express all needs
- Just because pictures are presented doesn't mean child will always go for them. Parent needs to teach them first
- Less upset
- Limited for expressing feelings

- Makes an event more tangible – puts a beginning middle and end
- Most people understand them
- Need a lot of pictures
- Needs to be consistency in pictures between home and school
- Needs to be individualised so cant just go buy any pictures sometimes
- Not always possible to show pictures
- Once child was less frustrated, parents were less frustrated
- Once they ask with pictures you cant refuse
- PECS book can be bulky to bring to places
- PECS book needs to be managed and updated regularly
- PECS is limited
- PECS is limited to how much you can express yourself
- PECS requires a lot of planning
- Physically putting images together may not be practical – practical element
- Pictures can be flimsy
- Pictures can be limited in amount of words child needs to express
- Pictures can tend to fall apart as they are used often
- Pictures limited in what they can express e.g. juice and flavour of juice
- Planning around visuals can be exhausting
- Planning Skills improved
- Positives outweigh the negatives
- Preparing really helps for big situations
- Rather speak to child then use pictures
- Requires a lot of planning
- Requires a lot of planning and thinking
- Schedules not always needed on a daily basis
- Solidified words in child's mind
- Some pictures can be abstract so you have to select based on your child's understanding
- Sometimes it doesn't always work
- Sometimes its hard to predict what is going to happen in a situation so harder to write a story if parent themselves doesn't know what's happening
- Sometimes pictures go missing
- Sometimes visuals can take time for child to learn something new
- Still a lot of mind reading to be done
- Takes a bit of getting your head around using it in the community
- Travelling with pictures can be cumbersome
- Trying to get the balance right between the child being comfortable and doing thinking for himself
- Uncertain as to whether child will need them forever
- Uses goodies – can be a negative
- Using child's interests can make it more appealing for child e.g. Favourite cartoon character
- Using pictures can require more than one person especially for training
- Using sweets to motivate child can be a disadvantage

- Using them to prepare for an event is helpful even though child may have experienced experience before because you never know how they are going to be that day
- Using visuals can feel like you are lowering your child's expectations especially if their speech is improving
- Visuals are more easily understood than verbal instructions
- Visuals are particularly useful for big changes
- Visuals can be rigid
- Visuals can be used even if child has no intellectual disability
- Visuals can be used for teaching academic skills
- Visuals can't replace language
- Visuals don't always work – if child is tired certain behaviours are inevitable
- Visuals don't necessarily make a family look different
- Visuals help a child 'see' what's happening
- Visuals help child verbalise not only wants but also experiences
- Visuals help keep routine and structure the home
- Visuals help other areas not only speech
- Visuals help the child
- Visuals helped child communicate needs – whether has speech or not
- Visuals helped parents reduce their language and remain calmer in tougher situations
- Visuals helped siblings and other family members
- Visuals kept it strict
- Visuals make explaining an instruction easier
- Visuals reduce anxiety
- Visuals take planning – can't just type it up – you have to go to places to take photographs especially for specific ones eg hospital appointment
- Were used more when child had no language
- When visuals don't work you are a bit like...?
- Word under picture helps with reading skills
- Words under pictures help others identify pictures if they are not clear
- Words under pictures help promote reading
- You can all understand pictures as opposed to sign language
- You can't have a visual for every single thing
- You can't have stories for every single little thing – child was getting used to this idea – schedule is helpful and can be quick
- You need desirable food items and most are poor eaters
- You need to remember to bring your visuals with you
- You need two people to teach them

Require Technology

- Laminator can break
- Lots of pictures on internet
- Pictures aren't always easy to understand
- Pictures aren't always universal

- Requires technology dropping pictures in a story – parent doesn't know how to do – but recognises you don't have to be very technological to do it – u can just paste pictures – but likes better how finished product looks with higher technology – nice to keep them in a folder
- Symbols aren't used universally
- Too many pictures of 'strawberries' on internet
- Velcro can be hard to find
- Velcro can destroy your clothes
- Visuals can be expensive to just buy
- You may need a lot of pictures
- You need to be a high tech person

Excerpt 4: Finalised Themes

P1

P2

P3

G (Group participants)

P5

P6

P7

1) Parent-Professional Partnership:

A) Shared planning and decision-making

Goals

- All totally new – introduced to them before they knew what it was totally about
- At first didn't want to use them – personal issues
- At first was resistant (felt was too regimented) but once started using and saw improvement decided to go with it
- Didn't fully understand why you would need them
- Didn't know what to think when first saw them
- Don't want to set up an expectation for the child if they are not followed through by professionals
- Experienced home tutor introduced them at home
- Hadn't heard about them before
- Hadn't seen them before
- Happy to go with professionals' recommendations – anything that would help
- Helpful if other professionals are on board with you
- Hesitant to start as you could do more harm than good
- Mum had been introduced to visuals through community early intervention services but she didn't quite understand what they were

- Mum took the initiative to try to understand more what they were before her child started school because they were also using visuals in that placement
- Never seen them before professional started using them
- Not mainstream knowledge to use visuals – only after you are told
- Only after diagnosis were we told of visuals
- Parent understood what visuals were as was familiar to them prior to clinic sessions – no problem understanding them as was exposed to them before
- Parents desperate for information
- Professionals decided what goals to work on
- Professionals introduced visuals
- Professionals not always on board with parents' goals
- Professionals told parents of pictures
- Professionals told parents to use visuals
- Professionals used them in the clinics – that's how parents initially exposed
- School staff first properly introduced mum to visuals
- Sometimes visuals aren't used in mainstream because teacher doesn't follow through
- Visuals aren't things you just think up yourself even though you see them all around you.
- You don't think that you are going to use them to e.g. dress your child

Parent-training

- Advice from other parents is more beneficial than professionals saying use visuals
- Clinic being all visual is helpful e.g. pictures of staff
- Course provided extra support as opposed to just watching other professionals
- Early bird helped to see different children, different situations, different schedules
- Follow up courses are helpful
- Frequent training is helpful – you don't always know it all
- Helpful to take any information from professionals
- Homework helpful
- Information on visuals was helpful
- Learning with other parents is more beneficial
- Lots of staff using pictures in the classroom setting
- Meetings with school staff helped parent understand visuals
- Mum saw how they worked in the classroom
- Professionals gave useful advice that was specific to child's needs
- School offered a lot of information
- Training also helpful to encourage other parents to use it
- Training didn't always apply to parents' situation
- Training helped
- Training was provided
- Training was useful. You might need to go back where you started.

- Video examples from other parents were more useful
- Watching other professionals use social stories helped
- Written information provided and helpful

Service provision

- After diagnosis, support was delayed – no access to courses therefore research done by herself
- Delayed and limited services
- Didn't know how to approach it with no support
- Didn't know if was doing it right
- Good support in school he was at
- Information provided but no support
- Little help provided
- More support needed to help parents feel more empowered to work with their child
- Most research was done by parent
- Never had a need to go and look up information – too much information out there
- Parents are not professionals
- Parents were told to get on with it
- Satisfied with the support
- Starting alone would have been very daunting
- Support has to be for everyone in house not only child with autism
- Support was poor – told about it but parent had to look it up
- Would be lost without support

B) Professionals' qualities

Understanding

- Professionals explained them quickly
- Support was specific to the child's needs
- When it was suggested parents didn't always understand what professionals meant
- You just get on with it

Trustworthy

(example not provided here as this is only an excerpt – illustrative quotes can be seen in Chapter 4)

Supportive

- Helpful when professional gives them a guide of a story to adapt
- Parents worked with professionals
- Professionals gave pictures to parents

- Professionals guided parents
- Showing how to use them and examples helped with parents' understanding
- Verbal support from school helped understand visuals

Knowledgeable

- Professionals appeared knowledgeable

2) Perceived changes in abilities and skills:

A) Perceived changes in children's skills

Communication

- Child knows what to do during routines
- Child understands events that may have not before e.g. Birthday
- Child understands expectations
- Child's understanding and expression improved
- Going to new school – specific events
- Helped starting conversations
- Helpful for daily routines e.g. toileting
- Helpful for making choices of preferred activities
- Improved cognitive processes
- Increased understanding of commands
- Now commenting
- Now expressing needs
- Now uses language
- Understanding change in routine/event improved
- Understanding of first/then improved
- Understanding of where they are going improved

Behaviour

- Behaviour improved
- Fewer frustrations
- Helped eating snack at school and new foods at home
- Improved confidence
- Less anxiety
- Less behaviour
- Less whinging
- Managing hair cutting better
- Token board for positive behaviours helpful

Pragmatic Skills

(example not provided here as this is only an excerpt – illustrative quotes can be seen in Chapter 4)

B) Perceived changes in parents' abilities and skills

Knowledge Acquisition

- Accepting diagnosis needed to come first before understanding visuals
- Always work in progress
- Mother is happier and more confident following the support she has received.
- Parent has more understanding of how to make up visuals
- Parent is more technological than they realise – confidence?
- Parent knows when child really needs visuals or whether a verbal message is enough
- Parents are coming up with new ways of how things might work for their child – more confident, trial and error works
- Parents come up with new creative ideas after they introduce visuals
- Parents have thought of creative ways on their own to use visuals – teaching stop/go, increasing language
- Parents learned as they went along
- The more they understood how they worked the more they could apply it to their child's needs
- They don't always see what you see in the pictures – recognising this has helped parents tailor make their pictures
- Using pictures was a trial and error process
- You can never say you know everything – never finished learning
- You can't get complacent, you are learning all along
- Parents felt they learned from sharing ideas in the focus group

Practice

- Obtaining the information on what they are and giving visuals a chance, is what helped mum to use them
- Parent happy with professional doing it
- Parent is confident they work

Action

- Parent cuts up and laminates
- Parent gathers information of steps involved
- Parent has folder of stories they use when needed
- Parent loves using them – helps that child likes them as well
- Parent organised them in a folder – child still likes looking at stories even though might not need them
- Parents became better at producing more high quality pictures – re sizing, laminating
- Parents make own visuals off internet or phone or specific apps, Google images, buy from shops – print and laminate

3) Experiences of using Visual Support Systems:

A) Enablers to using VSSs

Low-technology

(example not provided here as this is only an excerpt – illustrative quotes can be seen in Chapter 4)

Accessible

- Family members and other people can communicate with the child
- Including visuals with everyone in house doesn't make child feel excluded or put too much attention on one child
- Visuals can be used by all family members
- Visuals don't necessarily make a family look different

Effective

- A verbal message can be too quick
- Available for child to use when ever they want
- Can break down a task into very small steps
- Child enjoys looking at pictures
- Child is visual
- Child is visual
- Child likes using visuals
- Children very visual so uses a strength of theirs
- Count down helps break down a task
- Drawn into visuals straight away
- Easy to use as is simple and also shares moment with child when reading it – like reading a book
- Effective
- Encourages child to think for himself
- Found visuals helpful
- Gives child space to process what has been said
- Makes an event more tangible – puts a beginning middle and end
- Most people understand them
- Once child was less frustrated, parents were less frustrated
- Planning Skills improved
- Positives outweigh the negatives
- Preparing really helps for big situations
- Solidified words in child's mind
- Using child's interests can make it more appealing for child e.g. Favourite cartoon character
- Using them to prepare for an event is helpful even though child may have experienced experience before because you never know how they are going to be that day
- Visuals are more easily understood then verbal instructions
- Visuals are particularly useful for big changes

- Visuals can be used even if child has no intellectual disability
- Visuals can be used for teaching academic skills
- Visuals help a child 'see' what's happening
- Visuals helped parents reduce their language and remain calmer in tougher situations
- Visuals helped siblings and other family members
- Visuals make explaining an instruction easier
- Word under picture helps with reading skills
- Words under pictures help others identify pictures if they are not clear
- Words under pictures help promote reading
- You can all understand pictures as opposed to sign language
- Allows you to set up opportunities for more practices e.g. breaking cookie up into many pieces

B) Barriers to using VSSs

Time and Organisation

- At first visuals took time to make as parent needed to get right pictures, printing them, laminating them – can take hours/weeks, finding where to buy Velcro
- PECS requires a lot of planning
- Putting them together takes time
- Requires a lot of planning
- Requires a lot of planning and thinking
- Spend ages doing pictures and then might not be right for child
- Takes a bit of getting your head around using it in the community
- Technology requires time
- Time consuming
- Time consuming especially with lots of little pictures
- Trying to get free ones together is time consuming and requires planning
- Visuals take planning – cant just type it up – u have to go to places to take photographs especially for specific ones eg hospital appointment

Impractical

- Big book is bulky to carry, can be lost easily
- Breaking down what might be a simple task like getting dressed might actually require a lot of pictures
- Bulky to carry
- Can be an eye sore having pictures around house
- Can be costly
- Can be hard to gauge child's level of understanding with pictures – is he discriminating – especially if it doesn't bother child – Is he understanding where we are going? Or is he lazy/laid back?
- Can be impractical around the house – sticking up lots of pictures
- Can prepare for big events but sometimes things happen last minute

- Can't be used when there is an unplanned event like a fire engine sound
- Carrying all of them can be impractical though sometimes
- Changes happen unexpectedly
- Child followed visuals to a tee so parent felt needed to be adapted
- Child may want to eat them
- Child might decide a picture means something to them
- Child might interpret picture differently
- Children can be very literal – so HAS to be like picture – disadvantage of using them like when out and about – important that professionals tell you that it's black and white for children with autism not grey
- Children notice details in pictures that might be different to what they are thinking
- Constantly have to monitor PECS book
- Dealing with unexpected change can be hard to show with pictures – takes too much time and effort
- Didn't want child to be too dependent – and parent also to have to rely on same thing everyday
- Different pictures can represent same object
- Difficult to use PECS when child doesn't have many interests
- Difficulty using same picture in different environments
- Doesn't use them often now that child is ok with change
- Hard to plan for all events
- Hard to remember to bring PECS book each time
- Harder if extended family don't take on board visuals
- Has to be used consistently
- Having photographs of brands can be a disadvantage if they change packaging
- If child is having a meltdown getting visuals out at that stage isn't always very helpful
- If you made a promise with a visual and that changes, it can be hard for child with autism to deal with and for parent to explain
- It isn't enough to express all needs
- Just because pictures are presented doesn't mean child will always go for them. Parent needs to teach them first
- Laminator can break
- Limited for expressing feelings
- Lots of pictures on internet
- Need a lot of pictures
- Needs to be consistency in pictures between home and school
- Needs to be individualised so can't just go buy any pictures sometimes
- Not always possible to show pictures
- Once they ask with pictures you can't refuse
- PECS book can be bulky to bring to places
- PECS book needs to be managed and updated regularly
- PECS is limited
- PECS is limited to how much you can express yourself

- Physically putting images together may not be practical – practical element
- Pictures aren't always easy to understand
- Pictures aren't always universal
- Pictures can be flimsy
- Pictures can be limited in amount of words child needs to express
- Pictures can tend to fall apart as they are used often
- Pictures limited in what they can express e.g. juice and flavour of juice
- Planning around visuals can be exhausting
- Requires technology dropping pictures in a story – parent doesn't know how to do – but recognises you don't have to be very technological to do it – u can just paste pictures – but likes better how finished product looks with higher technology – nice to keep them in a folder
- Some pictures can be abstract so you have to select based on your child's understanding
- Sometimes it doesn't always work
- Sometimes its hard to predict what is going to happen in a situation so harder to write a story if parent themselves doesn't know what's happening
- Sometimes pictures go missing
- Sometimes visuals can take time for child to learn something new
- Still a lot of mind reading to be done
- Symbols aren't used universally
- Too many pictures of 'strawberries' on internet
- Travelling with pictures can be cumbersome
- Trying to get the balance right between the child being comfortable and doing thinking for himself
- Uncertain as to whether child will need them forever
- Uses goodies – can be a negative
- Using pictures can require more than one person especially for training
- Using sweets to motivate child can be a disadvantage
- Using visuals can feel like you are lowering your child's expectations especially if their speech is improving
- Velcro can be hard to find
- Velcro can destroy your clothes
- Visuals can be expensive to just buy
- Visuals can be rigid
- Visuals cant replace language
- Visuals don't always work – if child is tired certain behaviours are inevitable
- Visuals kept it strict
- When visuals don't work you are a bit like...?
- You can't have a visual for every single thing
- You can't have stories for every single little thing – child was getting used to this idea – schedule is helpful and can be quick
- You may need a lot of pictures
- You need desirable food items and most are poor eaters
- You need to be a high tech person

- You need to remember to bring your visuals with you
- You need two people to teach them

Stigma

- As child gets older visuals stick out more
- Don't want child to stick out as being too different
- Don't want him to get too reliant
- Other children in house can feel excluded if its only for child with autism
- Using visuals in front of siblings makes the child stick out as different – and parents don't always want to explain autism yet

Limitedness

(example not provided here as this is only an excerpt – illustrative quotes can be seen in Chapter 4)